DOCUMENT RESUME

ED 481 559 EC 309 866

TITLE	Understanding Disabilities in American Indian and Alaska Native Communities. Toolkit Guide.
INSTITUTION	National Council on Disability, Washington, DC.
PUB DATE	2003-08-01
NOTE	224p.
AVAILABLE FROM	National Council on Disability, 1331 F St., NW, Suite 1050, Washington, DC 20004-1107. Tel: 202-272-2004; TTY: 202-272-2074; Fax: 202-272-2022; Web site: http://www.ncd.gov.
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	EDRS Price MF01/PC09 Plus Postage.
DESCRIPTORS	*Alaska Natives; *American Indians; Assistive Technology; Change Strategies; Cultural Differences; *Disabilities; Elementary Secondary Education; Federal Legislation; *Health Services; Housing; Models; Program Development; *Special Education; Transportation; *Vocational Rehabilitation

ABSTRACT

This "toolkit" document is intended to provide a culturally appropriate set of resources to address the unique political and legal concerns of people with disabilities in American Indian/Alaska Native (AI/AN) communities. It provides information on education, health, vocational rehabilitation (VR), independent living, model approaches, and supporting documentation for improving services to people with disabilities living in Indian country. Following an introductory chapter, chapters address the following topics (sample sub-topics in parentheses): healthy living (health care, sports and recreation); education (federal special education law, Office of Special Education Programs strategic directions); independent living (model approaches, resources); vocational rehabilitation and employment (vocational rehabilitation basics for the consumer, consumer disability resources, tribal VR program resources); assistive technology (model approaches, resources); housing and facilities (universal design, making plans a reality); transportation (assessing service needs, model approaches, and making plans a reality); key elements of promising programs (leadership); advocating change (self-advocacy, sample resolutions); federal disability laws and tribes (understanding government-to-government relationships); and national initiatives, federal agencies, and national organizations. A disability etiquette handbook completes the toolkit. (DB)

Reproductions supplied by EDRS are the best that can be made
from the original document.

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

M.S. Quigley

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

1

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 481 559

Understanding disabilities

In American Indian & Alaska Native Communities.

TOOLKIT GUIDE

EC 309866

National Council on Disability
August 1, 2003

BEST COPY AVAILABLE

National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide

This report is also available in alternative formats and on NCD's award-winning Web site at www.ncd.gov.

Publication date: August 1, 2003

202-272-2004 Voice
202-272-2074 TTY
202-272-2022 Fax

The views contained in this report do not necessarily represent those of the Administration as this and all NCD reports are not subject to the A-19 Executive Branch review process.

About the Cover

The four symbols on the cover of the Toolkit Guide were chosen to represent the spectrum of disabilities, whether visible or hidden, that may be experienced by individuals in the American Indian and Alaska Native community. The universal meaning of each symbol is described in the captions below along with the meaning of the symbol as it is used in this Toolkit specifically.

Access for People Who Are Blind or Have Low Vision (blind with cane)
Universally, this symbol identifies areas that are specifically designed to be accessible to or in some cases tailored to the unique abilities of individuals who are blind or have low vision. Within the Toolkit, this symbol is used to represent the community of individuals for whom sight is not a primary sensory tool.

Mobility Access Symbol (wheelchair)
The wheelchair symbol indicates access for individuals who have a mobility disability, including individuals who use wheelchairs. The symbol is most commonly used to indicate an accessible entrance, bathroom, or environment that is sensitive to individuals with specific mobility access needs. Within the Toolkit, this symbol is simply used to represent the community of individuals with mobility needs of this kind.

Communication Access for People Who Are Deaf or Hard of Hearing (signing hands)
This symbol typically indicates that sign language interpretation is provided for a lecture, tour, performance, conference, or other program. Within the Toolkit, the symbol is used to represent the community of individuals whose primary means of communication is sign language.

Hidden Disabilities (face beneath face)
This symbol was designed specifically for the Toolkit after the Technical Expert Panel determined that there were currently only universal symbols for disabilities that are seen, leaving out the experiences of individuals with epilepsy, developmental disabilities, alcoholism, mental illness, learning difficulties, diabetes, and others who are not represented by the universal disability symbols. The symbol was inspired by the art of many indigenous cultures that designed faces with multiple overlaid masks. This symbol represents the community of individuals who have disabilities that are not externally visible but significantly impact an individual's life.

Acknowledgments

The National Council on Disability's (NCD) *Understanding Disabilities in American Indian and Alaska Native Communities: Toolkit Guide* was developed through the passionate collaboration of many individuals. The foundation of this project was formed in a powerful sharing of experiences, knowledge, and hopes among consumers and advocates who live with disabilities. These individuals strived to create a new perspective about what it means to be an American Indian or an Alaska Native with a disability. This new consciousness will serve to transform Indian communities nationally and offer a new hope to so many individuals who for so long have felt invisible with no voice.

NCD expresses its gratitude to the team at Kauffman and Associates, Inc., for drafting this toolkit. Team members include Project Director Dr. Martina Whelshula, Victor Paternoster, Tim Spellman, Wendy Thompson, and Ara Walline.

Others who have greatly supported the development of this work and deserve special acknowledgment are Mike Blatchford, consultant; Kathy Langwell and Project HOPE; Desautel Hege Communications; Robert Shuckahosee, consultant; Frank Ryan, consultant; the Consortia of Administrators for Native American Rehabilitation (CANAR); the American Indian Disability Technical Assistance Center; the American Indian Rehabilitation Research Training Center; the National Congress of American Indians (NCAI); focus group participants at NCAI and CANAR conferences; and Judy Babbit from the City of San Antonio Disability Access Office.

A special acknowledgment goes to those who represent the heart and soul of this effort, our Technical Expert Panel members: Mark Azure, Julie Anna Clay, Julia Davis-Wheeler, LaDonna Fowler, Joanne Francis, Joseph Garcia, Cordia LaFontaine, Carol Locust, Danny Lucero, David Miles, Damara Paris, Andrea Siow, H. Sally Smith, Raho Williams, Alvin Windy Boy. Thanks also to Jessie Stewart, age 10, for sharing her story.

In attempts to understand the complex make-up of Indian country as it addresses the needs of tribal members and descendants with disabilities, tribal program directors shared willingly about the challenges and inspirations experienced in their work. NCD

BEST COPY AVAILABLE

acknowledges these individuals and the tribes they represent: Jo White, Oglala Nation at Pine Ridge; Arlene Templer, Confederated Salish and Kootenai Tribes; Rita LaFrance, St. Regis Mohawk; Rhonda Talaswaima, Hopi Nation; Darlene Finley, Three Affiliated Tribes; Linda Pratt, Yakama Nation; Larry Alflen, Pueblo of the Zuni; Steven "Corky" West, Oneida Nation; Ella Yazzie-King and Paula Seanez, Navajo Nation; and Len Whitebear, Cook Inlet Tribal Council.

Technical Expert Panel

Several individuals representing consumers and advocates within the American Indian and Alaska Native disability community nationwide were recommended to serve as members of a national Technical Expert Panel. The Technical Expert Panel served as project consultants and advisors providing guidance to the staff on the direction of the project. The Panel was instrumental in providing critical feedback and direction on the multitude of issues addressed throughout the development of this toolkit. The Technical Expert Panel members are as follows:

Mark Azure
Tsimshian/Hunkpapa Lakota
Intertribal Deaf Council
Consumer

Julie Anna Clay
Omaha Tribe
Training and Dissemination Coordinator
American Indian Rehabilitation Research and Training Center (AIRRTC)
Consumer

Julia Davis-Wheeler
Nez Perce
Nez Perce Tribal Council
Chair, National Indian Health Board

LaDonna Fowler
Turtle Mountain Chippewa/Santee Sioux/Assiniboine
Chairperson, Subcommittee on Disability, National Congress of American Indians
Co-Founder, American Indian Rehabilitation Rights Organization of Warriors (AIRROW)
National Board Member, AIRRTC
Secretary, Multicultural Committee, National Council on Independent Living
Co-Secretary, Native American Alliance for Independent Living
Charter Member, Cultural Diversity Advisory Committee for National Council on Disability
Native American Disability Consultant/ Consumer

BEST COPY AVAILABLE

Joanne Francis
Akwesasne Mohawk
International Disability Consultant
Founding Member, AIRROW
Consumer

Joseph Garcia
Prairie Band of Potawatomi
Board Member – American Indian Disability Technical Assistance Center
Student, Salish Kootenai College
Consumer

Cordia LaFontaine
Consumer

Carol Locust
Eastern Band Cherokee
Indian Health Services Health Consultant
Cultural Sensitivity Trainer & Consultant
Consumer

Danny Lucero
Navajo/Apache Nations
Vice President, Intertribal Deaf Council
Gallaudet University
Consumer

David Miles
Nez Perce Tribe
Director, Nez Perce Vocational Rehabilitation Services
Board Member for the Idaho State Independent Living Council
Board Member for the Idaho State Rehabilitation Council

Damara Paris
Cherokee
President, Intertribal Deaf Council
Consumer

Andrea Siow
Hopi Nation
Consumer

H. Sally Smith
Tribal Leader
Alaska Native Health Board
National Indian Health Board

Raho Williams
Navajo Nation
Independent Living Specialist
San Juan Center for Independence
Consumer

Alvin Windy Boy
Chippewa-Cree
Tribal Leader
Rocky Boy Reservation

Toolkit Table of Contents

Getting Started

Welcome to the Toolkit 1
- How many Indians live on tribal lands? 2
- Did you know at least 555,000 Indians live with disabilities? 2
- What is a disability? 3
- What disabilities do we find in Indian communities? 4

Barriers and Challenges 5
References 8

Healthy Living

Background 9
Health Care 11
- Indian Health Service 12
- Medicaid 14
- Medicaid Home- and Community-Based Services (HCBS) 16
- Medicare 18
- State Children's Health Insurance Program (SCHIP) 19

Sports and Recreation 20
References 22
Appendix 25

Education

Background 27
Federal Special Education Law 28
- Individualized Education Programs 28
- Tips for Parents at IEP Meetings 29

IEP Checklist 30
Problem Solving 31
Office of Special Education Programs 31
Strategic Direction 1 32
Strategic Direction 2 33
Strategic Direction 3 34
Strategic Direction 4 36
Strategic Direction 5 38
OSEP-Sponsored Resources 39
IDEA Partnerships 40
Technical Assistance Alliance for Parent Centers 42
Technical Assistance and Dissemination Network—Minorities 43
References 46

Independent Living

Background 49
Model Approaches 51
ASSIST! to Independence 52
Native American Independent Living Services (NAILS) 53
Native American Advocacy Project (NAAP) 54
Resources 56
Federal Funding for Independent Living Centers 56
Statewide Independent Living Councils 57
Local Independent Living Centers 57
Independent Living Advocacy 58
References 60

Vocational Rehabilitation and Employment Resources

Background 63
VR Service and Employment Basics for the Consumer 64
Qualifying for Vocational Rehabilitation Services 64
Ticket to Work 65
Employment Protections 65
How to File Complaints 66
Consumer Disability Resources 68

Mental Health 69
Alcohol and Substance Abuse 70
Spinal Cord Injury 71
Traumatic Brain Injury 73
Tribal VR Program Resources 75
References 81

Assistive Technology

Background 83
Model Approaches 83
ASSIST! to Independence 86
Native American Advocacy Project (NAAP) 87
Resources 88
State Assistive Technology Financial Loan Programs and Other Loan Programs Serving Native Americans 89
General Assistive Technology Resources Available to Native Americans 89
Assistive Technology Advocacy 89
References 91

Housing and Facilities

Background 93
The Basics of Universal Design 94
Assessing Service Needs 96
Model Approaches 97
Making Plans a Reality 99
Whom do I contact first for help in making my home or work place accessible? 100
What legislation impacts housing for tribal members with disabilities and how do I file a complaint if the laws are not being honored? 100
Where do I learn more about universal design? 102
Whom can I contact for technical assistance, training needs, networking opportunities, and research information on housing? 103
What types of funding are available for tribal housing programs looking to create accessible facilities for tribal members, and how do I apply? 107
References 109

Transportation

Background 111
Assessing Service Needs 112
Definitions 113
Model Approaches 115
Pueblo of the Zuni 116
Confederated Salish and Kootenai Tribes 117
Other Programs 118
Making Plans a Reality 118
How do you find out about transportation services in your area? 119
What do you do if there are no transportation services in your area? 120
How do you assess the transportation needs and develop a service network in your community? 120
How do you find funding to support transportation services and programs? 124
Who provides assistance with compliance? 128
What legislation on the horizon could impact transportation service funding? How do you keep informed about the impact of pending legislation on transportation in tribal communities? 129
References 131

Key Elements of Promising Programs

Background 133
Leadership 134
Leadership Characteristics 135
Conclusion 137

Advocating Change

Self-Advocacy 139
Giving Voice to Your Life Choices 140
Speaking Up About Services 141
Step 1: Targeting 142
Step 2: Preparing 143
Step 3: Influencing 143
Step 4: Following Through 143

Guidelines for Writing a Resolution 144
Purpose of Submitting a Resolution 145
Resolution Format 145
Sample Resolutions 146
References 156

Federal Disability Laws and Tribes

Background 157
Understanding Government-to-Government Relationships 157
The Americans with Disabilities Act (ADA) and Tribes 158
The Rehabilitation Act and Tribes 159
The Individuals with Disabilities Education Act and Tribes 159
Advocacy 160
References 161

National Initiatives, Federal Agencies, and National Organizations

Background 163
Initiatives 163
Federal Disability Agencies 164
National Disability Organizations 170
References 182

Disability Etiquette Handbook

Dos and Don'ts 184
Conversation Etiquette 185
Glossary of Acceptable Terms 187
Preparing for Sign Language Interpreters 188
Resources Regarding Interpreters 189
Service Animals 190
What Is a Service Animal? 190
Service Animal Access 192
Service Animal Etiquette 192
Service Animal Resources 192
References 194

Getting Started

BEST COPY AVAILABLE

Mark Azure

"As a child when I moved to a deaf school off tribal lands I couldn't participate in my cultural rituals such as powwows and ceremonies. My life was like a torn piece of paper. When I could reconnect these ceremonies and my ability to be first a Native American and then a deaf person, my life came together again. This is what I want—to help rebuild our culture so everyone can do this."

BEST COPY AVAILABLE

Welcome to the Toolkit

A powerful voice in Indian country has emerged, strongly pronouncing that American Indian people with disabilities do not need to be "cured" or "fixed." In truth, equal access, fair accommodations, and an opportunity to make powerful contributions to our society are needed.

By eliminating the barriers, American Indian and Alaska Native (AI/AN) people with disabilities can work together in partnership to make tribal communities more accessible, more caring, and more representative of the beautiful, unique contributions each individual brings to this world.

> "Treat all men alike. Give them all the same law. Give them all an even chance to live and grow. All men were made by the same Great Spirit Chief. They are all brothers. The Earth is the mother of all people, and all people should have equal rights upon it.... Let me be a free man, free to travel, free to stop, free to work, free to trade.. free to think and talk and act for myself."
>
> *Chief Joseph, Nez Perce*

Indian people with disabilities and tribal leaders who served together on a Technical Expert Panel for the National Council on Disability (NCD) designed this Toolkit. They hope that the information, encouragement, and resources found in this Toolkit will help you and your community create the awareness, support, encouragement, and empowerment to improve the lives of people with disabilities and their families.

In this Toolkit, you will find information about disabilities, Indian tribes, and resources. You will also find suggestions for improving services, providing protections, and tapping resources in local tribal communities for people with disabilities. This guide will focus primarily on health care, independent living, education, and vocational rehabilitation. In addition, resources are provided in the areas of housing and transportation.

BEST COPY AVAILABLE

Each section of the Toolkit will provide specific contact information by topic for organizations that may be of further assistance to you. Where possible, the narrative describing each organization's mission and role has been directly quoted from the organization's Web site, and the Web site address has been identified in order to provide the most accurate and useful information.

AI/AN people with disabilities, especially those who live in Indian country, face unique circumstances and legal environments that require special outreach, consultation, protections, and services. There is a great desire among AI/AN people with disabilities to work in partnership with sovereign tribal governments to make tribal communities and work places accessible and welcoming to people with disabilities.

How many Indians live on tribal lands?

According to the 2000 U.S. Census, nearly 2.5 million Americans identify themselves exclusively as "American Indian or Alaska Native." There are 4.1 million people who identify themselves either as Indian only or Indian in combination with another race (Ogunwole, 2002). Of this total, approximately 944,433 Indian or Alaska Native people live on federal reservations or on off-reservation trust lands (Langwell and Sutton, 2002). Of the 50 states, 35 have federal reservations within or overlapping state borders.

The Federal Government, through the Bureau of Indian Affairs (BIA), officially recognizes 560 tribes and Alaska Native villages (Ogunwole, 2002). They are known as "Federally Recognized Tribes."

Did you know at least 550,000 Indians live with disabilities?

Data from the 1997 Survey of Income and Program Participation found that 22 percent of the American Indian and Alaska Native population has one or more disabilities (McNeil, 2001). This is the highest rate of disability when compared with all other races in the United States. The rate of disability varies significantly by race:

Race	Percentage with Disabilities
U.S. all races	20%
White	20%
Black	20%
Hispanic	15%
Asian	10%
American Indian	22%

If we consider only the 2.5 million who reported on the 2000 census that they identify themselves exclusively as "American Indian or Alaska Native," this means that at least 550,000 Indians and Alaska Natives have disabilities.

What is a disability?

The Americans with Disabilities Act (ADA) defines a disability as follows:

> The term "disability" means, with respect to an individual – (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impair–ment; or (C) being regarded as having such an impairment (42 U.S.C § 12101 et seq.).

"There is no uniform definition of disability since government agencies define disability differently.... Further clouding the picture, some health demographers do not define disability as completely as do rehabilitation demographers."

National Center for the Dissemination of Disability Research, 1999

Other, similar definitions are found in the Rehabilitation Act and the Social Security Act. You may find that eligibility for certain benefits, such as Social Security Income (SSI) for people with disabilities, may require a more rigorous definition. For example, the Social Security Act defines disability as follows:

> ...the term 'disability' means (A) inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months, or (B) blindness ...(42 U.S.C. 416 § 216 [42 U.S.C. 416] (1)(1))

BEST COPY AVAILABLE

While definitions vary, nearly all these definitions rely upon some measure of functional limitation to determine severity. This is done using activities of daily living (ADL) or instrumental activities of daily living (IADL).

> ADL include eating, walking, using the toilet, dressing, bathing, and getting in/out of bed.
>
> IADL include cooking, shopping, managing money, using a phone, doing light or heavy housework, and getting out of the home.

Assessing the severity of a disability is done by totaling the number of ADL or IADL experienced by an individual (NRCNAA, 2002).

What disabilities do we find in Indian communities?

Every type of disability that is found in the general population can also be found in the AI/AN population. Several small studies have surveyed tribal communities to identify most frequent types of disabilities. These studies (Clay, 1992; Rural Institute on Disabilities, 1995; AIDLP, 2000) generally found that the following types of disabilities are *most often* reported in Indian community surveys:

- Spinal cord injury (see Vocational Rehabilitation [VR] section for more information)
- Diabetes complications
- Blindness
- Mobility disability
- Traumatic brain injury (see VR section for more information)
- Deafness or hardness of hearing
- Orthopedic conditions
- Arthralgia
- Emotional or mental health conditions (see VR section for more information)
- Learning disabilities
- Alcoholism or drug dependence (see VR section for more information)

Not all disabilities are easily seen or can be seen at all. Many individuals have

hidden or unseen disabilities, such as emotional or mental health problems, learning disabilities, alcohol/drug dependence, or deafness. Some people are born with their disability, or develop the disability early in life. Other people acquire their disability later in life as a result of disease, age, or injury.

If we live long enough, we will each experience life with a disability.

Barriers and Challenges

Attitude: Most nondisabled people do not understand people with disabilities. Too often we see the disability and not the person. This is also true in our AI/AN communities. You can help change this!

Lack of Awareness: There is a lack of understanding about the number of Indians with disabilities, the types of disabilities in Indian communities, and the various opportunities our tribal government and service programs have to better protect and assist people with disabilities in Indian country.

Legal Enforcement Unclear: Federal laws designed to protect people with disabilities are not always enforceable against tribal governments because of the sovereign immunity and sovereign status of tribal governments. This does not mean that all enterprises located on tribal lands are exempt from federal laws, only that tribal governments are unique. Many tribes have opted to adopt their own ordinances and codes to protect Indian people with disabilities within the tribal system.

Rural Transportation: Most tribal lands are located in rural and remote areas of the United States and lack public transportation systems, which could provide people with disabilities with access to transportation and increased independence.

Rural Infrastructure: Tribal communities may not have the infrastructure to support access and accommodation for people with disabilities, such as sidewalks and sidewalk ramps for wheelchair access. Tribal communities may lack access to high-speed Internet or the means to acquire assistive technology for people with disabilities.

Public Access: Tribal and federal office buildings that serve the community are not always accessible for people with disabilities. Some tribes may lack the resources to retrofit their buildings to accommodate people with disabilities.

Complex Federal Programs: There are a variety of federal and state programs that can be important resources for people with disabilities on tribal lands. These programs may have overlapping or conflicting responsibilities and must be navigated with dogged determination. Don't take "no" for an answer.

State Relationships: Relationships between tribes and states can be strained because of overlapping or conflicting jurisdictions and other issues. States may offer many services and programs that can be helpful for people with disabilities and their families living in Indian country. It is important to remember that while tribes are sovereign governments, their members are also citizens of the state and of the United States and are entitled to access state programs.

Education Systems: The majority of AI/AN children are educated through the public school systems in each state. The balance of Indian children are educated in tribally operated schools or federal schools run by BIA. As a result, a variety of entities may have some level of responsibility for children with disabilities in our schools (Pavel, 1995). The Individuals with Disabilities Education Act (IDEA) requires public schools and BIA to provide children with disabilities with a free appropriate education based upon an Individualized Education Program for each child. This is the law. Parents of Indian children with disabilities may not be aware of the services and support their children are entitled to receive and may not know how to advocate for their children effectively.

Employment: Federally recognized Indian tribes are specifically exempt as employers under Title I of ADA, which prohibits discrimination against qualified individuals with disabilities in employment and requires that employers make reasonable accommodation for employees with disabilities (42 U.S.C. §§ 12101 et seq.). This exemption is a barrier for Indians with disabilities in Indian country, particularly in rural areas where tribal governments are the largest employer. Some tribal governments have voluntarily complied with ADA or adopted their own codes to protect people with disabilities from employment discrimination.

Housing: Homes are not generally designed to meet the needs of people with disabilities. There is limited funding at the tribal level to cover the cost of retrofitting tribal or private housing. This housing barrier can mean the difference between an individual with disabilities living independently or living under the care of others. Every home should have some means for "visitability" for people with disabilities.

Service Coordination and Advocacy: Indian people with disabilities do not always have a central location where services are coordinated within tribal settings. This can present a major barrier, particularly for individuals with disabilities who have multiple needs, such as housing, health care, vocational rehabilitation, and advocacy.

Personal Care Assistance: Just getting out of bed, bathed, dressed, and out of the house could present major barriers for some people with disabilities. Yet, with the support of a personal care attendant, many people with disabilities have been able to demonstrate their value as members of the tribal workforce. Much more can be done in Indian communities to provide home- and community-based services.

References

American Indian Disability Legislation Project (AIDLP) Research and Training Center on Rural Rehabilitation Rural Institute on Disabilities. (2000). Missoula: University of Montana Rural Institute.

Clay, Julie. (1992). A profile of independent living services for American Indians with disabilities living on reservations. Missoula: University of Montana Rural Institute.

Langwell, Kathy, and Janet Sutton. (2002). People with disabilities on tribal lands: Education, health, rehabilitation, and independent living literature review. Washington, DC: National Council on Disability.

McNeil, J. (2001). Americans with Disabilities 1997. *Current Population Reports: U.S. Census Bureau.*

National Center for the Dissemination of Disability Research (NCDDR). (1999). A review of the literature on topics related to increasing the utilization of rehabilitation research outcomes among diverse consumer groups. Retrieved November 4, 2002, from www.ncddr.org/du/products/dddreview/toc.html.

National Resource Center on Native American Aging (NRCNAA). (2002). *Functional Limitations and the Future Needs for Long Term Care.* Grand Forks: University of North Dakota.

Ogunwole, Stella U. (2002). The American Indian and Alaska Native population: 2000. *Census 2000 Brief: U.S. Census Bureau,* 1.

Pavel, D. Michael. (1995). Comparing BIA and tribal schools with public schools: A look at the year 1990-91. *Journal of American Indian Education* 35(1).

Rural Institute on Disabilities. (1995). American Indians and Disability. *Rural Facts,* 2.

Healthy Living

BEST COPY AVAILABLE

Damara Paris

"My disabilities are perceived by my American Indian and Alaska Native peers as a part of me. I do not feel as stigmatized as I do in mainstream society. At the same time, powwows and community tribal events are not sign language interpreted. How can I learn my traditions from my people without communication support?"

BEST COPY AVAILABLE

Healthy Living

Background

Healthy living expands the scope of health care by integrating a wellness approach, including sport and recreation activities. Wellness involves the mind, body, spirit, and context of the individual. Many Native American cultures emphasize harmony between mind, body, spirit, and one's relationship with one's community and the environment. In this way, today's health and wellness model may be highly compatible with the values of tribal members with disabilities.

Today's wellness model focuses on the optimal functioning of individuals regardless of disability or health status. Wellness spans a continuum that is unique to each individual and his or her context—a context composed of environmental factors such as culture, community, family, social networks, social history, and physical environment. More specifically, health and wellness may be measured in the following ways: the ability to function and have the option to do what one wishes; being independent and having self-determination with regard to choices, opportunities, and activities; having physical and emotional states of well-being; and not being held back by pain. Individual factors relating to health and wellness are

- Pain management
- Rest
- Exercise
- Nutrition
- Weight
- Skin care
- Medication

- Bodily functioning
- Sexuality
- Aging
- Attitude
- Identity
- Beliefs
- Self-determination
- Social contribution
- Consumer knowledge
- Personal growth and development
- Health management
- Social support
- Employment
- School
- Accessibility accommodation
- Personal assistant services
- Housing
- Transportation
- Knowledge and sensitivity of others, including health care providers
- Alternative/complementary medicine

Thus, individuals define their own wellness, which is based on individual circumstances and viewed holistically (ILRU, 2002).

The following section will describe the health or medical care support available for individuals with disabilities living in Indian country as well as provide an overview of the recreation and sport opportunities that also exist.

Health Care

People with disabilities depend upon health care systems to provide high-quality health services in accessible and appropriate settings. All Indian Health Service (IHS) and tribal health care facilities should be accessible for patients with mobility, sensory, or cognitive disabilities. Patients with hearing and visual disabilities should be able to access and communicate with their health care provider systems. Ramps, doorways, exam rooms, and restrooms must be accessible. Staff should be trained and prepared to effectively serve people with disabilities in the clinic.

IHS and tribal health care providers should review their health care system to ensure that the challenges faced by many Indians with disabilities are addressed and considered.

Never take "No" for an answer!
Even if you are declined for benefits, you should appeal that decision and work with an advocate or your local office to get any additional information you need to qualify.

Resources to meet the health care needs of Indians with disabilities are available through several existing programs. These programs are described below. Many of these programs can be used in combination with each other to provide an array of services most beneficial for the patient.

IHS and tribal health care programs can seek certification to bill for many services paid for by Medicaid, Medicare, or State Children's Health Insurance Program (SCHIP) and provide these services directly to patients in the clinics or through a home- and community-based services (HCBS) model. This is important for patients with disabilities who may require long-term care services.

BEST COPY AVAILABLE

Indian Health Service

AI/AN people have a unique relationship with the Federal Government. This relationship stems from Article I, Section 8 of the U.S. Constitution and is affirmed through numerous treaties, federal laws, Supreme Court decisions, and executive orders. A significant component of this relationship is the Federal Government's responsibility to provide health care services to Indian people.

The Federal Government carries out this responsibility through IHS, an agency within the Department of Health and Human Services (HHS). IHS is the primary health provider and health advocate for AI/AN people, and its goal is to raise their health status to the highest possible level. Unfortunately, IHS funding is never adequate for the challenge, and services are often rationed at the local level.

IHS is composed of 12 regional administrative offices known as Area Offices. Within each of these Area Offices, locally administered Service Units coordinate health services for tribal beneficiaries. Across the United States there are over 151 individual Service Units. Some Service Units are administered by the Federal Government, and some have been contracted by tribes, under the Indian Self-Determination Act (PL 83-638).

There are no "guaranteed benefits" for IHS patients. Services vary from one IHS/tribal clinic, health station, or hospital to the next. You must check with your local IHS or tribal health program to know which services are available. Services could include

- Outpatient medical services
- Inpatient hospital or specialty services (direct or referral)
- Dental services
- Mental health services
- Pharmacy and laboratory services
- Home nursing visits
- Community health representative visits
- Transportation

Eligibility for IHS Direct Services: To be eligible for "direct services" provided by the IHS directly or by a tribe, which administers services on behalf of the IHS, a person must be a member or a descendant of a federally recognized tribe. To be recognized as a descendant, an individual must show that he/she

- Is regarded by the community in which he/she lives as an Indian or Alaska Native;
- Is a member, enrolled or otherwise of an Indian or Alaska Native tribe or group under federal supervision;
- Resides on tax-exempt land or owns restricted property;
- Actively participates in tribal affairs; or
- Has any other reasonable factor indicative of Indian descent. (IHS, 2002)

In addition, IHS allows Indians of Canadian or Mexican origin who are recognized by any Indian tribe or group as a member of an Indian community served by the Indian program to also be eligible for IHS services. In certain cases, non-Indians can also be eligible for IHS services: for instance, a non-Indian woman who is pregnant with an eligible Indian's child or, in cases of public health hazard or acute infectious diseases, a non-Indian member of an eligible Indian's household.

Eligibility for IHS Contract Health Services (CHS): In cases where IHS or a tribal facility cannot provide within its own facility certain inpatient or specialty medical services, IHS can refer a patient to an outside or private provider. In these cases, the private provider or hospital will bill IHS for services to the patient. Due to limited funding, eligibility requirements for CHS are stricter than for services provided at an IHS or tribal facility. IHS/CHS eligibility requires that the IHS eligible patient also reside within a defined Service Delivery Area, which usually includes the counties overlapping or bordering the tribal reservation. It is important to note that prior approval from the IHS or tribal clinic is required for each CHS eligible service visit. Close coordination with the IHS or tribal clinic is required to effectively utilize CHS services.

How do I enroll? Your first visit should be with the IHS or tribal health clinic to register as a patient. You might be asked to name your tribe of enrollment or the tribe from which you descend on the registration form. In some cases, you might be asked to show your tribal identification card. For more information you can visit the IHS Web site at www.ihs.gov.

Medicaid

Medicaid is a federal program administered by the states. It was enacted in 1965 to pay for medical care for certain individuals with low income or lack of resources. For Indian and Alaska Native communities, it can help fill the gap in providing resources that might not be available through the IHS. It is also important to know that the IHS or tribal health clinic can bill Medicaid for services provided to Indian patients who are enrolled in Medicaid. This helps your local Indian clinic expand services.

Am I eligible? States decide who is covered, how providers get paid, and what services are covered under Medicaid. Eligibility can vary from state to state. At a minimum, the Federal Government requires states to cover

- Families with children who meet the Aid to Families with Dependent Children (AFDC) requirements in place on July 16, 1996 (former AFCD program)
- Poverty-level pregnant women and children
- People with disabilities who are enrolled in SSI

If an Indian or Alaska Native is enrolled in Medicaid, that program is required to pay for services before the IHS pays. Courts have determined that IHS is the "payer of last resort." States cannot restrict Medicaid eligibility based on medical condition, type of services needed, or place of residence.

Financial eligibility for Medicaid will be determined upon a review of income and resources. Most states use Supplemental Security Income (SSI) as the basis for determining financial eligibility, while some states develop their own formula to determine income and resources (Dixon, 2002).

What services are covered under Medicaid? Unlike IHS, Medicaid programs have a "defined benefits package" that each enrollee is entitled to receive. You can get these services at your local IHS clinic or at another clinic or facility. These packages vary from state to state, and some states might require a nominal co-payment by the patient for certain services.

Medicaid Mandated Services (states must cover):

- Inpatient hospital services
- Outpatient hospital services
- Physician services
- Nursing facility services for individuals age 21 and older
- Home health services for anyone entitled to nursing facility care
- Early and periodic screening, diagnosis, and treatment (for persons under age 21)
- Nurse-midwife services
- Family planning services
- Pediatric or family nurse practitioner services
- Other laboratory and X-ray services
- Dental services that would be covered if performed by a physician
- Intermediate care facility for mentally retarded
- Doctor of osteopath services for children under age 21 and pregnant women

Medicaid Optional Services (states can opt to cover):

- Nursing facility services for persons under age 21
- Home- and community-based services
- Hospice services
- Chiropractic services
- Private-duty nursing services
- Dental services
- Physical therapy
- Occupational therapy

- Services for people with speech, hearing, and language disorders
- Prescription drugs
- Prosthetic devices
- Eyeglasses
- Diagnostic, screening, prevention, and rehabilitation services
- Personal care services
- Pediatric immunizations
- Tuberculosis-related services
- Transportation
- Targeted case management services
- Institution for mental disease for individuals age 65 and over
- Inpatient psychiatric services for individuals under age 21

Making Medicaid Work for People with Disabilities: It is important to check with your state or local Medicaid Agency to see which services are covered. The Federal Government requires that home health services be provided if authorized by a physician. Services could include nursing, home health aides, medical supplies, medical equipment, and appliances suitable for use in the home (Dixon, 2002). Further, states can opt to expand this list to include personal care services, physical therapy, occupational therapy, speech pathology, audiology, rehabilitation, private-duty nursing, and transportation.

How do I enroll? Many IHS or tribal health clinics have business office staff or benefits coordinators who will help you fill out the necessary forms to apply for Medicaid enrollment. You can also go directly to your local, county, or state Medicaid office to apply.

Medicaid Home- and Community-Based Services (HCBS)

We used to think of long-term care as nursing home care. While nursing home care can be appropriate for some individuals, it is no longer the only option. In 1981, federal law was amended to allow state Medicaid programs to include HCBS waivers

(Social Security Act, Sect. 1915(c)). Today, all 50 states have implemented some type of HCBS waiver as an alternative to institutionalizing the elderly and people with disabilities.

The move to support de-institutionalizing people requiring long-term care received an important boost from the U.S. Supreme Court in 1999, when it ruled in *Olmstead v L.C.* (527 U.S. 581) that Title II of ADA requires states to provide community-based treatment for persons with mental disabilities when the providers determine that institutional care is inappropriate. The practical effect has been that states must now provide the "least restrictive care" for people with disabilities.

What can tribes do? Tribal health programs should review their state HCBS plans to see how tribally administered home- and community-based services can be paid through Medicaid reimbursement. In addition to the medical services offered by state Medicaid programs, states can also opt, by waiver, to provide case management, homemaker, home health aide, personal care, adult day health services, habilitation, respite care, and other related services. HCBS waiver programs may also provide services designed to foster independence, train family caregivers, and enable the individual to stay at home.

Who is most at risk for institutionalization? Unfortunately, the misuse of nursing homes, unnecessary physical restraints, and excessive referrals to large institutions has been a problem in communities across the United States for our elderly and people with severe disabilities (Shapiro, 1994). Those most at risk include the elderly, technology-dependent children, persons with traumatic brain injuries, persons with mental retardation or developmental disabilities, Alzheimer's patients, and others with severe disabilities (CMS, 2001).

Special Provisions for Children: Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program serves as Medicaid's well-child program, providing regular screening, immunizations, and access to care. When a problem is identified, EPSDT is used to confirm the diagnosis and cover appropriate treatment. EPSDT pays for the services. A state's HCBS waiver program can be used to provide Medicaid eligibility to children whose parents' income and resources exceed the usual thresholds. Such a waiver allows states to provide care at home or in their

communities to children who would otherwise be eligible for Medicaid only if they were institutionalized. States try to coordinate their HCBS and their EPSDT programs to look out for the best interests of the child and to make sure their special needs are met (CMS, 2001).

Medicare

Medicare is a federal program administered by the Federal Government though the Centers for Medicare and Medicaid Services (CMS). Medicare provides federal "health insurance" for hospital care (Part A) and medical care (Part B). In both programs, there can be some level of deductibles and co-insurance that must be paid by the patient. Medicare also provides preventive care benefits, including flu shots, mammogram screening, women's health screening, diabetes education, colorectal cancer screening, bone mass testing, and prostate test screening.

Part A coverage includes

- Hospital care
- Skilled nursing facility care
- Home health care
- Hospice care

Part B coverage includes

- Physician services
- Durable medical equipment
- Kidney dialysis and kidney transplants
- Outpatient hospital services
- X-rays and laboratory tests
- Limited ambulance benefits

Medicare does not generally cover costs associated with long-term care. The number of days of continuous care is limited under Medicare. Long-term care is generally covered by Medicaid.

Am I eligible for Medicare? Medicare provides coverage for certain types of health care services for the following groups of people:

- People age 65 or older
- Some people with disabilities (if receiving Social Security disability benefits for 24 months prior)
- People with end-stage renal disease (permanent kidney failure requiring dialysis or transplant)

If you are a person with disabilities and are under 65, and you have been entitled to Social Security disability benefits for at least two years, you will be automatically entitled to Medicare Part A beginning the 25th month of disability benefit entitlement.

How do I enroll? The Social Security Administration handles Medicare eligibility and enrollment. You can contact the Social Security Administration at 1-800-772-1213 to enroll in Medicare or to ask questions about your eligibility. You can visit their Web site at www.ssa.gov or at www.medicare.gov.

State Children's Health Insurance Program (SCHIP)

SCHIP was established by the Federal Government and is administered by the states, much like the Medicaid program. It is intended to be more flexible than the Medicaid program, but this varies from state to state. Some states will use their SCHIP dollars simply to expand their Medicaid program. Other states have established a stand-alone SCHIP program that targets children who might not be eligible for Medicaid but who still lack health insurance because of low income. You need to check with your local, county, or state health offices and ask about SCHIP coverage to know what is available in your state. Remember, federal law prohibits states from charging co-payments for SCHIP coverage to Native American children enrolled in the program. States are allowed to charge co-payments for SCHIP coverage, but *not* to Indian children.

Am I eligible for SCHIP? Your child or children might be eligible for SCHIP. Some states allow the entire family to be covered; most states cover only the children (www.cms.gov). The program is for children who do not currently have health insurance (IHS is *not* considered health insurance). Even if you are working, your child might still be eligible. Most states insure children up to 18 years old whose families earn up to $34,100 a year (for a family of four).

How do I enroll? You should contact your local IHS or tribal clinic to see if they will help you enroll your child or children in SCHIP. Remember, Indian children have *no* co-payment requirements under this program. You can also contact your local county or state health offices to enroll in SCHIP. For more information, see the SCHIP Web site at www.cms.gov/schip.

Sports and Recreation

Many options are available for people with disabilities with regard to recreation and sports. Community trips to movies and theater, spectator sports, sightseeing tours, museums, concerts, shopping, restaurants, and clubs help individuals with disabilities problem-solve, transfer therapy skills, and cope with real-life situations, especially as part of a rehabilitation program. Camps and camping are also important and popular forms of recreation for people with disabilities, and many organizations have camps designed for the special needs of people with disabilities. Sporting activities and organizations for people with disabilities include the following:

- Aquatics
- Archery
- Aviation
- Badminton
- Baseball
- Basketball
- Billiards
- Boccia
- Bowhunting
- Bowling
- Cycling
- Dance sport
- Fencing
- Fishing
- Goalball
- Golf
- Gymnastics
- Handball
- Hockey (floor, ice, ice sledge, sledge, and sled)
- Horseback riding
- Hunting
- Lawn bowling
- Martial arts
- Orienteering
- Power

As for sports programs, national, community, high school, and collegiate sports programs are primarily designed for people without disabilities. However, people with disabilities are frequently integrated into these "conventional" sports programs. There are advantages to integration as these programs usually have better coaching, better facilities, and more intensive training for their participants. In fact, ADA requires that community programs be accessible to people with disabilities, and IDEA requires that public school intramural and interscholastic sports programs be available to individuals with disabilities (Disability Sports, 2001b).

In 2001, HHS made increasing the number of physically active individuals with disabilities a public health priority. Research indicates that the benefits for anyone engaged in regular exercise (3 or more days per week for 20 or more minutes) are as follows:

- Physiological and psychological benefit
- Increased health-related physical fitness such as cardiovascular endurance, muscle strength, muscle endurance, and flexibility
- Weight control and the prevention of obesity and other health-related conditions
- Psychological benefits such as decreased anxiety and depression with improvements in emotions, self-esteem, and self-confidence (ILRU, 2001)

For people with disabilities, especially those with spinal cord injuries, vigorous physical exercise and sports (e.g., wheelchair sports such as basketball, bowling, track and field, swimming, archery, table tennis, softball, football, marathons, and rugby) are highly beneficial for

- Stimulating circulation
- Helping to prevent skin breakdown
- Increasing fluid intake
- Promoting self-worth and mental health
- Improving the immune system and overall health
- Reconnecting with the past and supporting a patient's construction of an identity following the injury
- Enhancing physical performance and inducing positive physiological adaptations

- Increasing community integration (PoinTIS, 2002)

Unfortunately, people with disabilities wishing to participate in sports are faced with numerous barriers:

- Sometimes people with disabilities find it difficult to believe in their abilities and to view themselves as athletes.
- Acceptance by teammates, coaches, officials, and sports administrators usually must be earned through performance, sportsmanship, and work ethic. A positive example from a team coach can help in this area.
- Access to quality coaching, programs, sports sciences services, and accessibility can be difficult. Many coaches and program directors still find difficulty in viewing athletes with a disability as deserving of attention and expertise.
- Athletes with disabilities frequently experience greater financial burdens associated with sports participation than nondisabled athletes because of increased costs associated with specialized equipment, personal assistance, insurance, and travel. (Disability Sports, 2002)

For tribal members with disabilities living on reservations, these barriers can seem insurmountable. However, organizations and resources are available to tribal members with disabilities who wish to participate in sports and recreational activities. In addition, tribal members with disabilities can also contact the nearest independent living center (ILC) for sports and recreation opportunities.

References

Center for Medicare and Medicaid Services (CMS). (2001). Fact Sheet: Home and Community Based Services. Washington, DC: CMS.

Disability Sports. (2002). Barriers to participation. Retrieved October 21, 2002, from http://ed-Web3.educ.msu.edu/kin866/issbarrier.htm.

Disability Sports. (2001b). Inclusion in "regular" sports programs. Retrieved October 21, 2002, from http://ed-Web3.educ.msu.edu/kin866/orgregular.htm.

Dixon, Mim. (2002). Opportunities for Medicaid financing of long term care in American Indian and Alaska Native communities. *American Indian and Alaska Native Roundtable on Long Term Care: Final Report*. Indian Health Service, 26.

Independent Living Research Utilization (ILRU) at TIRR. (2002). Definitions of health & wellness. Retrieved October 18, 2002, from www.ilru.org/healthwellness/healthinfo/wellness-definition.html.

Independent Living Research Utilization (ILRU) at TIRR. (2001). Physical activity, motivation and people with disabilities. Retrieved October 18, 2002, from www.ilru.org/online/handouts/2001/Kosma/motivating.html.

Indian Health Service (IHS). (2002) Eligibility requirements for health services from the Indian Health Service. Retrieved November 4, 2002, from www.ihs.gov/GeneralWeb/HelpCenter/CustomerServices/elig.asp.

PoinTIS Spinal Cord Injury Recreational Therapy. (2002). Recreational activities: Community trips, sports, independent living. Retrieved October 18, 2002, from http://calder.med.miami.edu/providers/RECREATIONAL/rec2.html.

Shapiro, Joseph P. (1994). *No Pity*. New York: Times Books.

Appendix

DEPARTMENT OF HEALTH & HUMAN SERVICES
Centers for Medicare & Medicaid Services
Disabled and Elderly Health Programs Group
7500 Security Boulevard, Mail Stop S2-14-26
Baltimore, Maryland 21244-1850

CMS
CENTERS for MEDICARE & MEDICAID SERVICES

Center for Medicaid and State Operations

Letter Summary

This letter clarifies some methods by which HCBS waivers under section 1915(c) may aid in the transitioning of individuals from institutional settings to their own home in the community through coverage of one-time transitional expenses. This clarification was promised in the HHS New Freedom Report to the President.

SMDL #02-008

May 9, 2002

Dear State Medicaid Director:

Medicaid home and community-based services (HCBS) waivers are the statutory alternative to institutional care. Many states have found in HCBS waivers a cost-effective means to implement a comprehensive plan to provide services in the most integrated setting appropriate to the needs of individuals with disabilities.

However, individuals seeking a return to the community from institutions are faced with many one-time expenses, and many states are unclear about the extent to which waivers cover transition costs. Examples of those expenses include the cost of furnishing an apartment, the expense of security deposits, utility set-up fees, etc. Other states have expressed interest in having the waivers pay for apartment/housing rent. This letter is designed to answer such questions.

Federal funding under Medicaid HCBS waivers is not available to cover the cost of rent. States may offset rental expenses from state-only funds that augment federal HCBS resources, but federal financial participation (FFP) for such a purpose is not available for any apartment/housing rental expenses.

As the HHS Report for the President's *New Freedom Initiative* stated, however, states may secure federal matching funds under HCBS waivers for one-time, set-up expenses for individuals who make the transition from an institution to their own home or apartment in the community, such as security deposits, that do not constitute payment for housing rent.

BEST COPY AVAILABLE

States may pay the reasonable costs of *community transition services*, including some or all of the following components:

- Security deposits that are required to obtain a lease on an apartment or home;
- Essential furnishings and moving expenses required to occupy and use a community domicile;
- Set-up fees or deposits for utility or service access (e.g. telephone, electricity, heating);
- Health and safety assurances, such as pest eradication, allergen control or one-time cleaning prior to occupancy.

By reasonable costs, we mean necessary expenses in the judgment of the state for an individual to establish his or her basic living arrangement. For example, essential furnishings in the above context would refer to necessary items for an individual to establish his or her basic living arrangement, such a bed, a table, chairs, window blinds, eating utensils, and food preparation items. We would not consider essential furnishings to include diversional or recreational items such as televisions, cable TV access or VCRs.

States that choose to include community transition services in their HCBS waivers must demonstrate that this service, in combination with other services furnished under the waiver, would be cost-neutral to the Medicaid program. (In the streamlined HCBS waiver format, this cost neutrality is demonstrated in appendix G.) To be eligible for FFP, the service must be included in the individual's written plan of care (service plan) and fit within the service definitions established by the state.

For more than three years CMS has awarded "Nursing Facility Transition Grants" to states in which transition costs have been paid from grant funds. Those states found that coverage of transition expenses has been manageable, cost-effective and has greatly facilitated the expeditious integration of individuals into their communities from prior institutional living arrangements. Contacts and other relevant information about those states may be found on the CMS website.

Any questions concerning this letter may be referred to Mary Jean Duckett at (410) 786-3294.

Sincerely,
/s/

Dennis G. Smith
Director

Education

BEST COPY AVAILABLE

LaDonna Fowler

"I believe Creator prepares us by what we go through, and my personal experiences have helped me build a toolkit of my abilities. The perspective I think we need to take is a national perspective, which is not just about our own tribe but about all native people."

EDUCATION

BEST COPY AVAILABLE

Education

Background

"There are approximately 500,000 American Indian and Alaska Native (AI/AN) students attending K-12 schools in the United States. Of the 500,000 AI/AN students, the majority (approximately 90 percent) attend public schools. The remaining 10 percent attend schools operated or funded by the Bureau of Indian Affairs (BIA) and Tribes" (Faircloth and Tippeconnic, 2000, p. 1). The Twenty-second Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (U.S. ED, 2000) reports that "American Indian students represent 1.0 percent of the general population and 1.3 percent of special education students. American Indian students slightly exceeded the national average in nine disability categories, reaching the largest percentages in the categories of deaf-blindness (1.8 percent) and traumatic brain injury (TBI) (1.6 percent)." These statistics suggest that AI/AN students are slightly over-represented in the special education population (Faircloth and Tippeconic, 2000).

For centuries now, educating Indian children has been a primary focus of government agencies and tribes. Boarding schools and other public education institutions have significantly affected the Indian community and how we look at education. The education of AI/AN children has reached crisis proportions as reflected in national and state data trends. So what happens to children with disabilities living in Indian country? What resources are available to children and parents?

The following section is designed to assist you by outlining federal education laws, by providing practical tips for parents, and by providing resources for technical assistance and protection.

Federal Special Education Law

On January 8, 2002, the federal law No Child Left Behind was signed by the President of the United States. This law holds educators, elected officials, policymakers, and parents accountable in an attempt to close the academic achievement gap between high- and low-performing students. The No Child Left Behind law allows parents to become involved in the development of district policies and plans for their child's education. Parents and community leaders can participate in school improvement efforts. This new law affects every school district in the country (Public Education Network, 2003). This law is especially important for rural, isolated schools such as those serving AI/AN children living on or near Indian country. Too many children are being left behind, and AI/AN children have historically fallen way below the national average in academic achievement compared with non-Indian children.

No Child Left Behind, in concert with IDEA, the federal special education law, can provide parents with new tools to ensure that their child's special education needs are being met. The Office of Special Education Programs (OSEP) administers IDEA, which guides the entire special education process. Special education programs follow rules and regulations set by federal and state governments. IDEA is implemented locally in all parts of the United States. As part of this law, OSEP of the U.S. Department of Education is responsible for meeting with each state and U.S. entity, including BIA, the Office of Indian Education Programs, and the Branch of Exceptional Education to ensure that the requirements of the law are being adequately met. Special education services in your area must meet these federal as well as local and state IDEA regulations (FAPE, 2002). The Act is authorized through 2002; the reauthorization process will be taken up in early 2003.

Individualized Education Programs

IDEA requires public school systems and BIA-funded schools to develop appropriate Individualized Education Programs (IEPs) for each child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student. IDEA also mandates that particular procedures be followed in the development of the IEP. Each student's IEP must be developed by a team of

knowledgeable persons and must be at least reviewed annually. The team includes the child's teacher; the parents (subject to certain limited exceptions); the child (if determined appropriate); an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents' or agency's discretion (DOJ, 2001).

Tips for Parents at IEP Meetings

The Arizona Center for Disability Law's Client Assistance Program (2002) offers both the tips and checklist that follow for parents who are working with their child's school to create an IEP that meets the unique needs of their child.

In arranging IEP meetings, you should remember the following:

- You or the school can ask that an IEP meeting be scheduled.
- Meetings to plan or review your child's IEP should be held when you can attend.
- If you cannot attend a meeting that has been scheduled, call the school immediately and ask that the meeting be rescheduled.
- The notice of the meeting should state the purpose, date/time, location, and participants of the meeting.
- Ask for an interpreter, if needed.

Prior to the IEP meeting you may prepare by doing the following:

- Set up an appointment to go to the school to review your child's school records.
- Ask for a copy of a blank IEP form so that you know what will be discussed.
- Get a copy of the school's proposed IEP, if one has been prepared.
- Get information and help from other parents or advocacy groups.
- Make a list of questions and comments to take to the meeting.

At the meeting you can be an effective team member in the following ways:

- By participating by a telephone call or a letter, if you cannot attend the meeting.
- By reminding the school, if necessary, that you will not sign a prepared IEP but wish to be involved in writing the IEP.

- By asking questions and sharing knowledge about your child with the team.
- By remembering that you may tape-record the meeting.
- By remembering that you may bring another parent, interested professional, or trained advocate with you.
- By knowing your child's rights and discussing these rights with the team.

At the close of the meeting

- Be certain that you understand your child's IEP. If you don't understand the IEP, ask the school to explain the services.
- Obtain a copy of the IEP.
- Though you should try to cooperate with the school, do not sign the IEP if it does not meet your child's needs.
- Request a due process hearing if you do not agree with the plan offered by the school (contact an advocate before requesting the hearing).
- Remember that the IEPs should be reviewed at least once per year.

IEP Checklist

Your child's IEP should contain all of the following:

- Information about the child's strengths and needs
- Measurable annual goals
- Short-term instructional objectives (short teaching steps that the team develops to allow each student to reach his/her annual goals)
- Services to be provided (including any related services needed to benefit from the school program such as transportation, physical therapy, occupational therapy, speech therapy, counseling, psychological services, or interpreter)
- Date each service will begin and end
- How progress will be measured
- Progress reports as often as children without disabilities receive them
- An explanation of the extent, if any, to which the child will not participate with nondisabled children in the regular classroom
- Transition services planning (beginning no later than age 14)

- Transition services programming (beginning no later than age 16) (Arizona Center for Disability Law, 2001)

Problem Solving

IDEA has procedures in place to allow any member of the child's IEP team to bring a problem to the attention of team members. The student's parents are given rights and protections called procedural safeguards. These rights allow parents to question decisions made by the school regarding their children's education (DOJ, 2001).

When disputes arise, IDEA favors solving the problem by both parties through a process called mediation (FAPE, 2002). The Consortium for Appropriate Dispute Resolution in Special Education (CADRE) is such an alternative that is funded by the U.S. Department of Education. CADRE encourages the use of mediation and other collaborative strategies to resolve disagreements about special education and early intervention programs. CADRE uses advanced technology as well as traditional means to provide technical assistance to state departments of education on implementation of the mediation requirements under IDEA '97. CADRE also helps parents, educators, and administrators benefit from the full continuum of dispute resolution options that can prevent and resolve conflict and ultimately lead to informed partnerships that focus on results for children and youth (CADRE, 2002).

For a more detailed description of due process and complaint process guarantees provided for AI/AN children and families under IDEA, please refer to the Federal Disability Law and Tribes section of the Toolkit.

Office of Special Education Programs

OSEP has developed five strategic directions designed to improve education results for students with disabilities (OSEP, 2002). These directions are based on research and outreach that focused on what is currently working for students, parents, teachers, and schools. These directions are also closely tied to the IDEA legislation. OSEP was in fact the sponsor of the research that preceded the legislation. The following descriptions of the strategic directions and the brief information about the

projects, publications, technical assistance centers, and clearinghouses are quoted directly from the U.S. Department of Education's Web site in order to provide you with the most complete information possible. More detailed information can also be obtained by contacting OSEP directly:

Phone: (202) 205-9675

Web site: www.ed.gov/offices/OSERS/OSEP

Strategic Direction 1: Infants, Toddlers, and Their Families Receive the Supports They Need

The first weeks and months of an infant's life can significantly affect all aspects of his/her entire life, including success in school. Data and anecdotal information indicate that families all across the country often are not informed early enough about the importance of early intervention. Too often children with significant disabilities may be 2 or 3 years old before they are referred for assessment and early intervention. Schools have a great stake in early identification and service provision for all eligible infants and toddlers and their families. Relevant state agencies must develop strong interagency partnerships to ensure a continuous, effective campaign to identify children in need of early intervention.

It is also equally important that our youngest children and their families receive services and supports in natural environments. Services provided in the home, childcare, or other community-based settings are reporting positive responses from families and the early childhood community. Moreover, children who start off in settings with their peers who don't have disabilities are more likely to be included throughout their school years.

IDEAs That Work for Infants and Toddlers

Project: "Supporting Neurobehavioral Organizational Development in Infants With Disabilities: The Neurobehavioral Curriculum for Early Intervention"

Phone: (206) 285-9317

E-mail: mgallien@halcyon.com; anotari@wri-edu.org

The goal of this project is to provide curriculum for parents and professionals so that/ they can support the neurobehavioral organization of infants born with very low birth/ weight or with severe disabilities./

Project: Circle of Inclusion Web Site/

Web site: www.circleofinclusion.org/

This Web site offers demonstrations and information about the effective practices of/ inclusive educational programs for children with disabilities (birth through age eight)./

Technical Assistance Center: National Early Childhood Technical Assistance System (NECTAS)

Phone: (919) 962-2001

TTY/TDD: (919) 962-8300

Web site: www.nectas.unc.edu

Technical Assistance Center: Technical Assistance Alliance for Parent Centers - The Alliance

Phone: (888) 248-0822

TTY/TDD: (612) 827-7770.

Web site: www.taalliance.org

Strategic Direction 2: Preschool Programs That Prepare Children with Disabilities for Elementary School Success

In 1986, half as many children attended preschool programs as today and only 24 states participated in the preschool program. Today all states have a preschool program for children with disabilities. It is not good enough just to offer the child a program. The program must be rigorous and prepare children for success in school. OSEP supported a study with the National Academy of Sciences on preventing reading failure in young children. This study showed that a rich preschool program can make a difference. It is also important that in those programs children have opportunities to have an integrated experience with their nondisabled peers. We must make sure that our preschool programs are preparing children to be successful in the primary grades.

Project: Reaching Individuals with Disabilities Early (RIDE Project)

Web site: www.ovec.org/ride/Home/index.htm

RIDE is a model demonstration project with the goals of

1.- Enhancing child-find efforts in targeted school districts by distributing multifaceted awareness packages and

2.- Helping school districts to develop local capacity in the delivery of assistive technology services, by providing an intensive training program.

Project: Language Is the Key

Web site: www.wri-edu.org/bookplay

A video-training program designed to address the needs of professionals and paraprofessionals who work with young children with language disorders.

Publication: Preventing Reading Difficulties in Young Children

Web site: www.nap.edu

Technical Assistance Center: National Early Childhood Technical Assistance System (NECTAS)

Phone: (919) 962-2001

TTY: (919) 962-8300

Web site: www.nectas.unc.edu

Strategic Direction 3: Effective Intervention for Young Students with Reading or Behavior Difficulties

The importance and effectiveness of strategies that intervene early in a child's development are well recognized in improving results for children with disabilities. Unfortunately, approximately 60 percent of the children currently being served under IDEA are typically identified too late to receive full benefit from such interventions. This problem is most prominent with two specific populations of children: those identified for special education and related services under the categories "specific

learning disabilities" and "emotional disturbance." These children are often not identified as being eligible for special education and related services until after their disabilities have reached significant proportions. These are children who very early in their education experience marked difficulties learning to read or exhibit behaviors that lead to discipline problems as they get older.

A body of research on the topic tells us how to assess, identify, and help these children. For instance, research indicates that

- Both populations of children can be assessed and identified early and with relative ease and accuracy;
- Both populations of children, based on the nature of their disabilities, are at high risk for dropping out of school, becoming discipline problems, and for failing in school;
- Both populations of children need valuable time that is essential to learning, time often lost because these children do not receive appropriate services earlier; and
- Both populations can make tremendous gains when provided with effective services during early childhood.

In practice, however, schools and teachers simply are not prepared to implement effective research-based practices to meet the needs of these children. We must join with our general education partners to ensure that all children experiencing early reading or behavior difficulties receive the services they need.

IDEAs That Work for Children with Reading or Behavioral Difficulties

Budget Request: The President has proposed, for the fiscal year 2000 budget, a $50 million dollar initiative called PRIME TIME: Reading and Behavior Initiative that will support demonstrations of school-based models of effective programs and practices to serve children who have marked difficulty learning to read and/or who exhibit behaviors that lead to discipline problems as they get older.

Project: National Center on Accelerating Student Learning (CASL)/

Phone: (615) 343-4782/

E-mail: lynn.fuchs@vanderbilt.edu; doug.fuchs@vanderbilt.edu/

Promoting success in reading, writing, and math in grades K–3. CASL is a five-year/ research effort designed to accelerate learning for students with disabilities./

Publication: "Early Warning, Timely Response; A Guide to Safe Schools"/

Phone: (877) 4ED-PUBS/

Web site: www.ed.gov/offices/OSERS/OSEP/earlywrn.html/

Technical Assistance Center: Center for Effective Collaboration and Practice (CECP)/

Phone: (202) 944-5454/

Web site: www.air-dc.org/cecp/default.htm/

Technical Assistance Center: Center on Positive Behavioral Interventions and Support/

Phone: (541) 346-3560/

E-mail: PBIS@oregon.uoregon.edu./

Strategic Direction 4: Appropriate Access to the General Education Curriculum

It is critically important that children with disabilities have access to the same curriculum that other children have if they are going to become successful adults. Simply put, children with disabilities should be learning what other children are learning in school and schools should be held accountable for results. Current research indicates that a large number of children with disabilities are not learning the same things in school as other children and therefore are not going to be in a position to graduate from high school or to be successful in life. The IDEA '97 amendments provide access to the general curriculum by requiring that states include students with disabilities in nationwide assessments. It is important that we manage our programs based on the results of these assessments.

IDEAs That Work to Ensure Access to the General Education Curriculum

Project:- Performance Assessment and Standardized Testing for Students with Disabilities: Psychometric Issues, Accommodation Procedures, and Outcome Analysis

Web site: www.wcer.wisc.edu

This project focuses on how fourth- and eighth-grade students with and without disabilities function on math and science assessments.

Publication: "A Curriculum Every Student Can Use: Design Principles for Student Access"

Web site: http://ericec.org/osep-sp.html/

Published by the OSEP-sponsored ERIC/OSEP Special Project; ERIC Clearinghouse on/ Disabilities and Gifted Education/

Technical Assistance Center: National Center on Educational Outcomes (NCEO)/

Phone: (612) 626-1530/

Web site: www.coled.umn.edu/nceo/

Technical Assistance Center: The National Center to Improve the Tools of Educators (NCITE)

Phone: (541) 686-5060

Web site: http://darkwing.uoregon.edu/~ncite/index.html

Technical Assistance Center: The Parents Engaged in Educational Reform Project (PEER)

Phone: (617) 482-2915

Web site: www.fcsn.org/peer

Technical Assistance Center: Consortium on Inclusive Schooling Practices (CISP)

Phone: (412) 359-1600

Web site: www.pgh.auhs.edu/CISP

Technical Assistance Center: National Institute for Urban School Improvement/

Phone: (303) 620-4074/

TTY/TDD: (703) 519-7008/

E-mail: Elizabeth_Kozleski@ceo.cudenver.edu/

Strategic Direction 5: All Students with Disabilities Complete High School

Despite recent U.S. Department of Education reports of improvement data, for a number of years, national statistics have indicated that students with disabilities drop out of school at a higher rate than nondisabled students do, and if they stay in school, often complete their program without a standard diploma. This is still the case in Indian country. We need to be committed to graduating special education students with diplomas that represent the attainment of skills and knowledge necessary to succeed in adult life. We need to remember that higher education and lifelong learning are stepping stones for everyone. We also have to recognize that education and employment go hand in hand. We need to prepare our students to earn their way to success. OSEP-sponsored research has shown that monitoring students, building adult-student relationships, increasing the student's connection to school, and improving student problem-solving skills, along with ensuring access to general and vocational curricula, all play a part in increasing a student's chances of successful high school completion.

IDEAs That Work to Help Students with Disabilities Complete High School

Project: The National Transition Alliance (NTA)

Web site: www.dssc.org/nta

NTA has identified over 25 promising programs from across the country addressing dropout prevention. A database of these programs is at the Web site above. Use the search term "dropout." The NTA's purpose is to promote the transition of youth with disabilities toward desired post-school experiences.

Project: "Building Responsive High School Special Education Programs"

Web site: www.ced.appstate.edu/projects/special_ed

This project is working in two high schools to improve the outcomes for students with disabilities who are at risk of dropping out.

Publication: "The ABC Dropout Prevention and Intervention Series"
Institute on Community Integration
Publications Office, University of Minnesota
150 Pillsbury Drive SE
Minneapolis, MN 55455

Phone: (612) 624-4512

A series of four booklets outlining effective dropout prevention and intervention strategies for middle school and beyond.

Technical Assistance Center: The National Transition Alliance for Youth with Disabilities (NTA)

Web site: www.dssc.org/nta

Clearinghouse: The National Information Center for Children and Youth with Disabilities

Web site: www.nichcy.org

Clearinghouse: HEATH Resource Center

Phone: (800) 544-3284 (voice, TTY)

Web site: www.acenet.edu/Programs/HEATH/home.html

OSEP-Sponsored Resources

IDEA authorizes formula grants to states and discretionary grants to institutions of higher education and other nonprofit organizations to support research, demonstrations, technical assistance and dissemination, technology and personnel development, and parent-training and information centers. These programs are intended to ensure that the rights of infants, toddlers, children, and youth with disabilities and their parents are protected.

Office of Special Education and Rehabilitative Services/
U.S. Department of Education/
400 Maryland Avenue SW/
Washington, DC 20202/
Phone: (202) 205-5507/
TTY/TDD: (202) 205-5637/
Web site: www.ed.gov/offices/OSERS/OSEP/index.html/

IDEA Partnerships

OSEP funds four national projects, called IDEA Partnerships, to deliver a common message about the landmark 1997 reauthorization of IDEA. The IDEA Partnerships, working together for five years, inform professionals, families, and the public about IDEA '97 and strategies to improve educational results for children and youth with disabilities (IDEA Practices, 2002). The IDEA Partnerships include the following:

The Council for Exceptional Children
The Associations of Service Providers Implementing IDEA Reforms in Education (ASPIIRE)
1110 North Glebe Road, Suite 300
Arlington, VA 22201-5704
Phone: (877) CEC-IDEA
TTY/TDD: (866) 915-5000
Fax: (703) 264-1637
Web site: www.ideapractices.org

The ASPIIRE IDEA Partnership builds upon the strengths of 19 associations to assist practitioners in providing positive outcomes for students with disabilities. ASPIIRE utilizes collaboration to observe and learn from service providers in educational settings and translate needs into guidance, accurate resources, and training opportunities. Utilizing rapid-response systems with a vast information dissemination network, the ASPIIRE IDEA Partnership acts as a pivot point for distilling complex regulations into effective, research-based practices. The Partnership continually taps the strengths and expertise of its members.

The Families and Advocates Partnership for Education (FAPE)

Partnership at the PACER Center

816 Normandale Boulevard

Minneapolis, MN 55437-1044

Phone: (888) 248-0822

TTY/TDD: (952) 838-9000

Fax: (952) 838-0199

Web site: www.fape.org

The FAPE Partnership at PACER Center aims to inform and educate families and advocates about IDEA '97 and promising practices. The FAPE Partnership links families, advocates, and self-advocates to communication of the new focus of IDEA '97. The FAPE Partnership has developed family-friendly curricula and materials addressing the requirements of IDEA '97, positive behavioral supports, new research, and other issues of concern to families. These resources are also available in multiple languages through the FAPE Web site.

The Council for Exceptional Children

ILIAD IDEA Partnership

1110 North Glebe Road, Suite 300

Arlington, VA 22201-5704

Phone: (877) CEC-IDEA

TTY/TDD: (866) 915-5000

Fax: (703) 264-1637

Web site: www.ideapractices.org

The ILIAD IDEA Partnership delivers support to the ongoing efforts of local education administrators and leaders. As the country continues to implement IDEA, the ILIAD Partnership brings together the preeminent educational leadership associations and builds upon their strengths and expertise. Together these groups interact to determine multiple vehicles for providing information, proven strategies, and technical assistance to school districts in urban, suburban, and rural areas.

The Policymaker Partnership (PMP) at the National Association of State Directors of Special Education

1800 Diagonal Road

Suite 320

Alexandria, VA 22314

Phone: (877) IDEA-INFO

Fax: (703) 519-3808

Web site: www.ideapolicy.org

PMP operates to increase the capacity of policymakers to act as informed change agents who are focused on improving educational outcomes for students with disabilities. The organizations that partner with PMP have profound influence in promoting excellence and equity for students with disabilities in the public education agenda.

Technical Assistance Alliance for Parent Centers

Parent Training Centers, funded by the U.S. Department of Education, are located all across the country. One example of these programs is the AI/AN Families Together Parent Training and Information Center, in Moscow, Idaho, which recruits and trains community members to provide support and assistance to families of AI/AN children with disabilities (NCD, 2002). Parent centers in each state provide training and information to parents of infants, toddlers, school-aged children, and young adults with disabilities and the professionals who work with their families. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. To reach the parent center in your state, you can contact the Technical Assistance Alliance for Parent Centers (the Alliance), which coordinates the delivery of technical assistance to the Parent Training Centers and the Community Parent Resource Centers through four regional centers located in California, New Hampshire, Texas, and Ohio.

Technical Assistance and Dissemination Network—Minorities

The Alliance Project for Tribal Colleges and Universities
PO Box 340
Wilmot, SD 57279
Phone: (800) 984-9406
Fax: (605) 938-4786
E-mail: jim@dailypost.com
Web site: www.alliance2k.org/introduction

The Alliance Project is funded by OSEP. The Project seeks to address the increasing demand for qualified personnel from historically under-represented groups in special education and related services. A major emphasis of the Alliance Project is to increase the success rate of special education and related services departments in acquiring grants from the OSEP Division of Personnel Preparation (DPP). The purpose of these grants is to prepare personnel in special education and related services to meet the demand for qualified professionals and to build institutional capacity.

Alliance engages in technical assistance and information services for the preparation of DPP grant proposals and for institutional development. Activities include grant writing workshops, mentoring, and best practice seminars. The Project works with faculty members in departments of general and special education, allied health and health sciences, school psychology, and counseling at historically Black colleges and universities, tribal colleges, and other institutions of higher education whose enrollment includes at least 25 percent of students from historically under-represented groups who are citizens of the United States. These groups include Hispanics, African Americans, Native Americans, and people with Asian ancestry.

AI/AN teachers and paraeducators are needed in K–12 special education settings. The Alliance Project for Tribal Colleges works to help meet this need. During the initial Alliance 2000 Project, 14 tribal colleges and universities (48 percent) submitted DPP grant proposals with Alliance assistance. Seventy-one percent of these proposals were successfully funded.

Linking Academic Scholars to Educational Resources (LASER)

Department of Special Education

University of South Florida

4202 East Fowler Avenue, EDU 162

Tampa, FL 33620

Phone: (813) 974-1385

Fax: (813) 974-5542

E-mail: btownsen@tempest.coedu.usf.edu

Web site: www.coedu.usf.edu/LASER

LASER's mission is to enhance the capacity of faculty and graduate students in minority institutions to engage in research that affects children from minority and/or low-income backgrounds. Access the latest research, resources, news, and events in the field of special education. Learn about new research programs designed for scholars who are committed to the plight of impoverished youth. Provocative online discussions focus on urgent topics facing our nation's most challenged schools. Join the effort to narrow the gap between special education research and practice.

National Information Center for Children and Youth with Disabilities (NICHCY)

PO Box 1492

Washington, DC 20013

Phone: (800) 695-0285

Fax: (202) 884-8441

E-mail: nichcy@aed.org

Web site: www.nichcy.org

NICHCY's services are made possible through funding from OSEP and operated by the Academy for Educational Development. NICHCY shares information about disabilities and disability-related issues regarding children and youth via their Web site and publications. It will connect you with state and national resources, free of charge, in English or Spanish. Anyone can use its services—families, educators, administrators, journalists, students. Its special focus is on children and youth (birth to age 22). NICHCY compiles disability-related resources in each state and creates State Resource Sheets. These handy resource sheets will help you locate the

following people, organizations, and agencies within your state that address disability-related issues:

- Governors and U.S. Senators/
- State agencies serving children and youth with disabilities/
- State chapters of disability organizations and parent groups/
- Parent training and information projects/

References

Arizona Center for Disability Law, Client Assistance Program (CAP). (2001). Educational rights of students with disabilities: A self-advocacy guide. Retrieved September 27, 2002, from www.acdl.com/pdfs/SE1.pdf.

CADRE, The National Center on Dispute Resolution. (2002). Retrieved September 27, 2002, from www.directionservice.org/cadre/about.cfm.

Faircloth, Susan, and John W. Tippeconnic III. (2000). Issues in the education of American Indian and Alaska Native students with disabilities. Retrieved September 27, 2002, from www.ael.org/eric/digests/ecord003.htm.

Families and Advocates Partnerships for Education (FAPE). (2002). The Individuals with Disabilities Education Act (IDEA). Retrieved September 30, 2002, from www.fape.org/idea/index.htm.

IDEA Practices On-line. (2002). Retrieved September 27, 2002, from www.ideapractices.org/about/aspiire.php.

Langwell, Kathy, and Janet Sutton. (2002). People with disabilities on tribal lands: Education, health, rehabilitation, and independent living literature review. Washington, DC: National Council on Disability.

National Association of State Directors of Special Education On-line. (2002). Implementing the No Child Left Behind Act: What it means for IDEA. Retrieved September 27, 2002, from www.nasdse.org.

National Information Center for Children and Youth with Disabilities. (2002). Retrieved September 30, 2002, from www.nichcy.org.

Office of Special Education Programs (OSEP), U.S. Department of Education. (1999). Executive summary: Report of Bureau of Indian Affairs special education program evaluation. Retrieved December 17, 2002, from www.dssc.org/frc/nmpp/MonitoringReports/BIASelf-Assessment.pdf.

Office of Special Education Programs (OSEP). (2002). IDEAs that work: OSEP's five strategic directions. Retrieved September 27, 2002, from www.ed.gov/offices/OSERS/OSEP.

Public Education Network. (2003). An action guide for community and parent leaders. Retrieved January 6, 2003, from www.publiceducation.org/pubs/pubpreorder/orderform.asp.

Technical Assistance Alliance for Parent Centers. (2002). Parent training and information centers and community parent resource centers. Retrieved September 27, 2002, from www.taalliance.org/PTIs.htm.

U.S. Department of Education (U.S. ED). (2000). Twenty-second annual report to Congress on the implementation of the Individuals with Disabilities Education Act (IDEA). Washington, DC: U.S. Government Printing Office. Retrieved December 30, 2002, from www.ed.gov/offices/OSERS/OSEP/Products/OSEP2000AnlRpt/PDF/Chapter-2.pdf.

U.S. Department of Justice (DOJ), Civil Rights Division, Disability Rights Section. (2001). A guide to disability rights laws. Retrieved September 27, 2002, from www.usdoj.gov/crt/ada/cguide.htm.

Independent Living

BEST COPY AVAILABLE

Raho Williams

"Sometimes when an elder leaves the home to live in an institutional setting their spirit is just lost. The foundation of the family is gone and the cultural unity of the family suffers. When it is appropriate, day care can help elders and we can see a difference with this personal care. We have a lot of work to do to be recognized and know how to access services like these."

BEST COPY AVAILABLE

Independent Living

Background

In essence, independent living is a philosophy that people with disabilities have the same rights, choices, and options as anyone else. It is the belief that one should have opportunities to make decisions affecting one's own life and pursue activities of one's own choosing. This philosophy emphasizes self-determination with an individual having the freedom to learn from one's own experiences (ILRU, 2002).

Such a philosophy marks a radical departure from the traditional rehabilitation perspective in which a disability is seen as a deficit and as a limitation. The independent living philosophy offers individuals the opportunity to choose a role other than victim, patient, or sufferer. In the independent living perspective, an individual's disability is not the emphasis. Rather, the independent living perspective emphasizes the individual's right to the types of help and assistance that the individual chooses. Although living on one's own and having a job suited to one's capabilities, for example, are critical aspects of independent living for many people, more important is the individual's decision to live or work according to his/her own desire that more accurately defines independent living (ILRU, 2002).

A comparison of traditional rehabilitation and independent living service models in five categories (Limitations, Label/Role, Objectives, Organizational Structure and Response, Community and Self-Perceptions of Person with a Disability) shows this difference in philosophy. The rehabilitation model views limitations as physical impairments resulting in functional limitations related to walking, seeing, hearing, learning, etc. The independent living service model, on the other hand, views limitations as the community barriers, including stereotypes, stigma, prejudice, discrimination, low expectations, and structural barriers, that people with disabilities must navigate in order to have an active life of their choosing. In the area of labels

TRADITIONAL REHABILITATION AND INDEPENDENT LIVING PARADIGM COMPARISON
(COMPARISON OF SERVICE MODELS)

ISSUE	REHABILITATION	INDEPENDENT LIVING
LIMITATIONS	Impairments resulting in functional limitations related to walking, seeing, hearing, learning, etc.	Community barriers, including stereotypes, stigma, prejudice, discrimination, expectations and structural barriers.
LABEL/ROLE	Patient, victim, sufferer	Person with a disability, advocate, consumer
OBJECTIVES	Fix deficits to overcome limitations.	Systems change to reduce structured inequality, disability awareness to minimize restrictive perceptions
ORGANIZATIONAL STRUCTURE AND RESPONSE	Control is vested in professionals Knowledge base is advanced degrees. Professional counseling Professional therapy	Control is vested in person(s) with disabilities. Knowledge base is experiential, focusing on achieving independence. Peer support and counseling Independent living skills training
COMMUNITY AND SELF-PERCEPTIONS OF PERSON WITH A DISABILITY	A person who, as a result of a disability, is unable to participate in a variety of roles due to lack of function.	A person identified as having a disability, who, as a result of community perceptions and structural barriers, is restricted from participating in a variety of social roles, including roles related to education, employment, recreation, social, worship, civic activities, etc.

(Impact, Inc.)

BEST COPY AVAILABLE

and roles, it is not uncommon for the rehabilitation model to consider an individual with disabilities as a patient, victim, or sufferer. The independent living philosophy would describe the same individual as a "person with a disability," an "advocate," or a "consumer." The objective of the rehabilitation philosophy is to fix deficits and to overcome limitations. Independent living service models seek systems change to reduce structured inequality and disability awareness to minimize restrictive perceptions. In the area of organizational structure and response, the rehabilitation model vests control in professionals. The knowledge base is advanced degrees, professional counseling, or professional therapy. The independent living service model seeks to vest control in the person(s) with disabilities. The knowledge base is experiential, focusing on achieving independence. Peer support and counseling are recommended. Independent living skills training is provided. Finally, there are differences in the community and self-perceptions of a person with a disability. The rehabilitation model would identify a person who, as a result of a disability, is unable to participate in a variety of roles due to lack of function. The independent living model would see a person identified as having a disability as someone who, as a result of community perceptions and structural barriers, is restricted from participating in a variety of social roles, including roles that relate to education, employment, recreation, social, worship, and civic activities.

By valuing diverse perspectives and approaches to living in and contributing to one's community, the independent living concept offers tribes the opportunity to develop services and programs for tribal members with disabilities that are tailored to their own unique cultures. This philosophy invites tribal members and communities to tap into and express their deeply held values and beliefs. For some this may mean taking a wellness approach; for others, seeking balance; for still others, deepening their understanding of traditional healing or of their own tribe's teachings. For tribes, designing a program to assist tribal members with disabilities can be part of a larger healing journey.

Model Approaches

In the United States, independent living organizations with an emphasis on Native Americans are a relatively new concept. However, three organizations have pioneered in this area, providing independent living services specifically to Native Americans.

Each of the three programs that follow exemplifies unique approaches to providing independent living programs and services to Native Americans, as well as additional services designed to meet the needs of the Indian communities they serve:

ASSIST! to Independence

PO Box 4133

Tuba City, AZ 86045

Phone: (928) 283-6261; (888) 848-1449

Voice/TTY: (928) 283-6672

Fax: (928) 283-6284

E-mail: assist@cybertrails.com

Web site: www.assisttoindependence.org

The mission of ASSIST! to Independence is to provide culturally relevant services to a cross-disability American Indian consumer population. Each of its programs emphasizes a common goal of enhancing quality of life and community life through maximizing independence and improving functional skills. These services are provided in an environment that promotes active consumer and family participation in self-determination and equal opportunities. ASSIST! to Independence is a community-based, American Indian–owned and –operated nonprofit agency that was established by and for people with disabilities and chronic health conditions to help fill some of the gaps in service delivery (ASSIST!, 2002a).

ASSIST! provides services primarily to the Navajo, Hopi, and Southern Paiute Reservations; however, anyone needing information or assistance in the northern part of the state is welcome to request services. The agency serves as a consumer-driven community action program to facilitate general awareness of disability-related issues, community access, education, information sharing, assistive technology access, advocacy, and independent living that is culturally appropriate for American Indians. This is done through a comprehensive collaborative network, which provides support and resources that promote the active participation of each individual in his/her self-care management. Program staff provide the tools necessary for individuals to make informed choices and decisions; to maintain a maximum level of independent living; to achieve equality of opportunity, inclusion, and integration in the community and society; and to attain economic and social self-sufficiency (ASSIST!, 2002a).

ASSIST! serves as the umbrella organization for five major programs: (1) The Regional Resource Center for Assistive Technology; (2) The Center for Independent Living; (3) The Special Needs Toy Lending Library; (4) The Functional Assessment Clinic; and (5) The Sensory Integration Program. ASSIST! provides the four core independent living services of (1) information and referral; (2) independent living skills training; (3) individual and systems advocacy; and (4) peer mentoring. In addition to these four core services, ASSIST! also provides traditional healing, home modifications and environmental interventions, durable medical equipment, and nonemergency transportation to medical appointments for individuals who qualify (ASSIST!, 2002a).

ASSIST! attributes its success to the following:

- ASSIST! services are dynamic and fluid in nature, so they are able to respond fairly quickly to current needs within the community.
- ASSIST! believes in understanding and immersion in the culture they are serving, and respecting differing cultural needs.
- ASSIST! uses aggressive outreach promoting "wellness" services, as opposed to services targeted primarily for people with disabilities.
- ASSIST! uses extensive and comprehensive collaborations and networking within the community.
- ASSIST! develops close working relationships with "nontraditional disability specialists," such as community health representatives, senior centers, and public health nurses.
- ASSIST! has a visible presence within the community. They attend many senior functions and all health fairs promoted by Chapter Houses within communities across the reservation (ASSIST!, 2002b).

Native American Independent Living Services (NAILS)

3108 Main Street

Buffalo, NY 14214

Voice/TDD: (716) 836-0822

Fax: (716) 835-3967

E-mail: info@wnyilp.org

Web site: www.wnyilp.org

NAILS is a program of the Western New York Independent Living Project in Buffalo, New York. NAILS serves the Six Nations Confederation in the Western New York region. This federally recognized program has successfully assisted hundreds of American Indians with disabilities with independent living services. Services and programs are provided to American Indians with disabilities living on three reservations and in area cities and communities. NAILS provides its services to members of the Onondaga, Oneida, Cayuga, Mohawk, Seneca, and Tuscarora Tribes (Native American Independent Living Services, 2002a).

All requests for services, communication, and information relating to services received are kept strictly confidential. NAILS provides advocacy, peer support, information and referral, independent living skills instruction, mental health support groups, family support services, service coordination/case management, and a family reimbursement program. NAILS is considered a walls-free program delivering its services through a mobile office service system. Services are delivered to consumers in their homes rather than the consumers going to an independent living center (ILC) (Native American Independent Living Services, 2002b).

NAILS attributes its success to the following:

- NAILS hires staff from each of the nations it serves to work in those nations, thus maintaining and developing trust between NAILS staff and the tribes and consumers whom they serve.
- NAILS has worked to develop staff cultural competency, helping them to understand the unique cultures of the nations they serve as well as to understand the unique government-to-government relationships each tribe has with state governments and with the Federal Government, which vary. (Dougherty, 2002)

Native American Advocacy Project (NAAP)

PO Box 527

208 South Main Street

Winner, SD 57580

Phone: (605) 842-3977; (800) 303-3975

TTY: (605) 842-3977

Fax: (605) 842-3983

E-mail: admin@sdnaap.org

Web site: www.sdnaap.org

The mission of the Native American Advocacy Project is to empower members of the American Indian Oyate in South Dakota who have developmental, physical, mental, and/or neurobiological disabilities to actualize their potential by providing them with education, training, advocacy, support, independent living skills, and referrals to them and their Tiospaye (Native American Advocacy Project, 2002).

NAAP is a statewide, nonprofit, consumer and family membership organization for persons residing on and off lands of the nine tribal nations in South Dakota. NAAP is chartered both with the State of South Dakota and the Rosebud Sioux Tribe (where NAAP's central office is located). NAAP is committed to providing support to the developing role of Native American consumers (persons with all types of disabilities) and their family members in system planning, decisionmaking, networking, advocacy, and service development for these populations. NAAP is also committed to being a cross-disability organization; they are inclusive of persons with all types of disabilities, not limiting efforts to only one or two disability groups but strengthening efforts on behalf of all persons with disabilities. This approach provides support to those disabilities that have been under- or unrepresented in the disability movement (Native American Advocacy Project, 2002a).

NAAP operates the Tateya Topa Ho (Voice of the Four Winds) program, which is an intertribal ILC "without walls" that provides services to individuals with disabilities living on reservations and tribal land and in unserved areas throughout South Dakota. Services are provided on a local basis so that individuals are able to become independent in their own environment, rather than having to leave their homes, families, and communities. Independent living services and support systems are provided by Native individuals with disabilities or local/tribal service providers. The four core independent living services to consumers with disabilities are information and referral, advocacy, peer support, and independent living skills training. Independent living skills training includes such things as food preparation

and shopping, homemaking skills, budget management, leisure activities/recreation, interpersonal skills, and communication skills (Native American Advocacy Project, 2002b).

Resources

Independent living technical assistance organizations provide valuable assistance to Native American tribes, Indians with disabilities, and program and service providers. The American Indian Disability Technical Assistance Center (AIDTAC), for example, helps tribes create holistic plans to fill gaps in their infrastructure; modify or create laws and policies that reduce independent living barriers; review, modify, or create laws and policies that facilitate employment opportunities for members with disabilities; coordinate disability issues on reservations; expand, improve, or create services by identifying potential links; and facilitate cooperative agreements with nontribal organizations. In addition, AIDTAC assists nontribal agencies in working with tribes in such a way that culture and sovereignty are respected; provides a national network of tribal programs, nontribal organizations, and consumers who advocate for issues related to Indians with disabilities at the tribal, state, regional, and national levels; and identifies, recruits, and mentors American Indians and Alaska Natives with disabilities who are in leadership positions. These organizations usually have organizational and funding ties to institutions of higher learning.

Federal Funding for Independent Living Centers

Independent living services and centers are funded through Title VII of the Rehabilitation Act. Title VII provides funds that states may use to provide independent living services, develop and maintain state ILCs, and improve working relations between independent living programs, ILCs, state independent living councils, vocational rehabilitation, supported employment, and other federal and nonfederal programs established or supported through the Rehabilitation Act. Funds to provide independent living services are available through a grant mechanism. Tribal governments may apply to receive a Title VII grant. Grants are administered through the Rehabilitation Services Administration (NCD, 2002).

Statewide Independent Living Councils

In the independent living process, statewide independent living councils (SILCs) are full partners with vocational rehabilitation through the 1992 amendments to the Rehabilitation Act. Their primary responsibility is collaboration with state vocational rehabilitation agencies in the development of a state independent living plan, determining how Rehabilitation Act (Part B) funds are used, monitoring the plan, reviewing the plan, and evaluating the implementation of the plan (Independent Living, 2002).

State governors appoint members to each SILC after soliciting recommendations from organizations that represent a broad range of individuals with disabilities. Those appointed are knowledgeable and committed to disability rights and the independent living philosophy. Tribal representation is authorized under the Rehabilitation Act. In states where Section 121 (tribal vocational rehabilitation grant) projects have been awarded, one member of the council is required to be a director of one of those projects (29 U.S.C. § 796D(b)(2)(C)). The 1992 amendments to the Rehabilitation Act seek consumer control by requiring that the majority of an SILC's membership be individuals with disabilities not employed by ILCs or state agencies (Independent Living, 2002).

Local Independent Living Centers

The Rehabilitation Act of 1978 created a system of ILCs to serve individuals with severe disabilities. Independent living centers, or centers for independent living (CILs), are nonprofit organizations that are typically nonresidential, consumer-controlled, and community-based. They provide services and advocacy by and for people with disabilities. The goal of these organizations is to help people with disabilities to reach their maximum potential in their families and communities. In addition, these organizations serve as an advocate for national, state, and local independent living issues. The 1992 amendments to the Rehabilitation Act require that these organizations have a majority of individuals with disabilities on their staff and governing boards.

ILCs/CILs seek to provide services to individuals with disabilities from cross-disability and multicultural populations. The core services that ILCs/CILs provide are

- Systems and individual advocacy

- Peer counseling
- Information and referral
- Independent living skills training

These organizations may also provide assistance in finding and obtaining accessible housing, financial benefits counseling, equipment loan and/or repair, personal assistance services, employment readiness services, and services that relate to identifying, hiring, training, and firing a personal assistant (Research and Training Center on Independent Living, 2002).

Native American consumers and providers would benefit by contacting the ILC/CIL nearest to their reservation. Although most ILCs/CILs do not have a specific Indian focus, they provide services to individuals with disabilities from cross-disability and multicultural populations.

Independent Living Advocacy

The idea of independent living has ties to the civil rights movements of the 1960s and 1970s. Activities included forming community-based groups of people with disabilities working together to identify barriers and gaps in the delivery of services. To address these service delivery barriers, action plans were developed that focused on educating the community and influencing policymakers at all levels in order to introduce legislation to remove these barriers and to change policies and regulations (Mountain State Center for Independent Living, 2002).

The Independent Living Movement works for anti-discrimination legislation and equal opportunity for services, allowing people with disabilities the same degree of control over their lives as people without disabilities, and has people with disabilities take the initiative in the design of services, which maximizes individual consumer choice and control. In addition, the Independent Living Movement believes that people with disabilities must demonstrate, to themselves and to the public, that they are fully capable of taking the independent living cause in their own hands as the movement is based on the principles of self-determination, self-help, and consumer control (disAbility Resource Center, 2002).

Advocacy provides a mechanism by which consumers and professionals can influence policy and program decisions affecting individuals with disabilities. Self-advocacy places value on individuals taking control of their lives and acting in their own best interest. Self-advocacy requires an individual to be linked to information, understand complex rules, repeatedly communicate one's needs to an impersonal bureaucracy in an effective manner, and be persistent. Systems advocacy, in particular, seeks to improve policy responsiveness, increase resource sharing, and facilitate program access (Clay, 2002).

Systems advocacy may also present itself as an obstacle for individual Indians with disabilities because of the complex relationships between tribal governments, state governments, and the Federal Government that make targeted advocacy efforts difficult. However, systems advocacy has been critical to tribal governments in their goal to exercise self-determination and in the passage of the Self-Determination Act of 1976. Thus, through national organizations and an ILC structure on a reservation,

References

ASSIST! to Independence. (2002a). ASSIST to independence. Retrieved September 26, 2002, from www.assisttoindependence.org/ati.

ASSIST! to Independence. (2002). Round peg in a square hole: Independent living in Indian country. Retrieved September 26, 2002, from www.assisttoindependence.org/ati/peg.html.

ASSIST! to Independence. (2002b). Competition regarding best CIL practices in rural outreach to emerging disability populations. Retrieved September 26, 2002, from www.assisttoindependence.org/ati/bestpractices.html.

Clay, Julie Anna. (2002). Native American independent living. Retrieved October 7, 2002, from www.aidtac.org/NativeIL.htm.

disAbility Resource Center. (2002). Independent living. Retrieved September 19, 2002, from www.wa_ilsc.org/independ.html.

Dougherty, Ken. (September 24, 2002). Telephone interview by Victor Paternoster.

Impact, Inc. (2002). IL & rehabilitation paradigm comparison. Retrieved September 19, 2002, from www.impactcil.org/phil_history/il_rehab.htm.

Independent Living Research Utilization (ILRU). (2002). Directory of SILCs. Retrieved September 20, 2002, from www.ilru.org/jump1.htm.

Langwell, Kathy, and Janet Sutton. (2002). People with disabilities on tribal lands: Education, health, rehabilitation, and independent living literature review. Washington, DC: National Council on Disability.

Mountain State Center for Independent Living. (2002). History of the independent living movement. Retrieved September 19, 2002, from www.mtstcil.org/skills/il-2-intro.html.

Native American Advocacy Project. (2002a). Homepage. Retrieved September 26, 2002, from www.sdnaap.org.

Native American Advocacy Project. (2002b). Tateya Topa Ho. Retrieved September 26, 2002, from www.sdnaap.org/tateya.htm.

Native American Independent Living Services (NAILS). (2002a). NAILS. Retrieved September 26, 2002, from www.wnyilp.org/NAILS/NAILS.html.

Native American Independent Living Services (NAILS). (2002b). Services. Retrieved September 26, 2002, from www.wnyilp.org/NAILS/services.html.

Research and Training Center on Independent Living. (2002). Independent Living Concept Fact Sheet.

Virtual CIL. (2002). Directory of independent living centers. Retrieved October 8, 2002, from www.virtualcil.net/cils.

Vocational Rehabilitation & Employment Resources

BEST COPY AVAILABLE

Joseph Garcia

"People have ideas about disabilities but they don't know what it's like. They might want to hold you back. I still have all the mechanical knowledge from running heavy equipment but just because I can't do that anymore, I can still do things like change the transmission on my car by myself."

VOCATIONAL REHABILITATION

BEST COPY AVAILABLE

Vocational Rehabilitation and Employment Resources

Background

Vocational rehabilitation (VR) programs vary greatly from state to state and tribe to tribe. Tribal VR programs may differ significantly depending on a tribe's cultural and geographical environment. Vocational rehabilitation is more than job placement or counseling services. It is a comprehensive service uniquely tailored to the local culture and community needs. The George Washington University's Department of Counseling, Human and Organizational Studies (2002, p. 1) suggests that rehabilitation counselors "...are concerned with assisting individuals who have disabilities with maximizing their potential and their independence." This assistance entails comprehensive counseling services, which include the individual, group, and family, in addition to multicultural counseling and addressing the attitudinal and environmental barriers for people with disabilities. Rehabilitation counseling may also encompass more complex services and counseling approaches such as medical and psychosocial aspects of disability and job development and placement, which are all regulated by strict ethical standards for rehabilitation counselors (Department of Counseling, Human and Organizational Studies, 2002).

Unfortunately, not all tribes have a VR program. The U.S. Department of Education, through the Rehabilitation Act of 1973, funds tribal VR programs on a competitive basis. The average award of this Section 121 grant program is $350,000. Because grants are awarded on a competitive basis, tribes who may have had VR services in the past could lose their VR funding during the next funding cycle, and those tribes who have never had VR funding could be awarded a grant for the first time. This situation presents a number of problems for tribes who are attempting to provide a much-needed service to their tribal members and descendants with disabilities.

In light of these unpredictable changes, this section of the Toolkit will (1) familiarize the consumer with VR services and employment resources and (2) provide ideas and resources to existing tribal VR programs and/or to those tribes who are planning to develop their own VR program.

VR Service and Employment Basics for the Consumer

The Rehabilitation Services Administration (RSA) was established by Congress to protect the employment and rehabilitation rights of people with disabilities. The RSA provides national leadership for, and administration of, basic state and formula grant programs, service projects, and rehabilitation training discretionary grant programs. These programs develop and implement comprehensive and coordinated programs of vocational rehabilitation, supported employment, and independent living for individuals with disabilities through services, training, and economic opportunities in order to maximize their employability, independence, and integration into the work place and the community (U.S. ED, 2002).

Under Title I of the Rehabilitation Act of 1973, as amended, states receive federal grants (through the Department of Education) to operate a comprehensive VR program. These funds are awarded to designated state VR agencies within each state. This state-operated program is designed to assess, plan, develop, and provide VR services to eligible individuals with disabilities, consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice.

RSA's major Title I formula grant program provides funds to state VR agencies to provide employment-related services for individuals with disabilities, giving priority to individuals who are significantly disabled (U.S. ED, 2002).

Qualifying for Vocational Rehabilitation Services

An "individual with a disability" means any individual who

- has a physical or mental impairment that constitutes or results in a substantial impediment to employment for the individual; and
- can benefit from VR services to achieve an employment outcome.

To be eligible for VR services, an individual must

- be an "individual with a disability," as defined above; and
- require VR services to prepare for, secure, retain or regain employment.

(Minnesota Workforce Center, 2002)

RSA is unique in that it specifically addresses drug or alcohol addiction (Section 504 covers former users and those in recovery programs and not currently using drugs or alcohol), in addition to emotional and psychological problems, as a disability. This recognition is important when assessing and serving the needs of AI/AN communities.

Ticket to Work

On the employment front, a portion of President Bush's New Freedom Initiative announced on February 1, 2001, included swift implementation of the Ticket to Work Incentives Improvement Act of 1999. The goal of the program is "to give disability beneficiaries the opportunity to achieve steady, long-term employment by providing them greater choices and opportunities to go to work if they choose to do so" (Social Security Administration [SSA], 2002). The legislation also "removes barriers that previously influenced people's choices between healthcare coverage and work" (SSA, 2002). By 2003, all states and territories will have this program implemented.

Ticket to Work

Phone: (866) YOURTICKET; (866) 968-7842
TDD: (866) TDD2WORK; (866) 833-2967
Web site: www.yourtickettowork.com

Employment Protections

Titles I and II of ADA also specifically address employment issues for individuals with disabilities. However, Title I categorically excludes tribes as employers (42 U.S.C. § 12111(5)(B)(i)). This exclusion applies to the sovereign status of tribes. Other businesses on the reservation do not necessarily fall under this categorical exclusion. Title I requires employers with 15 or more employees to provide qualified individuals with disabilities with an equal opportunity to benefit from the full range of employment-

related opportunities available to others. For example, it prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities, and other privileges of employment. It restricts questions that can be asked about an applicant's disability before a job offer is made, and it requires that employers make reasonable accommodation for the known physical or mental disability of otherwise qualified individuals with disabilities, unless it results in undue hardship. Title II covers all activities of state and local governments regardless of the government entity's size or receipt of federal funding. Title II requires that state and local governments give people with disabilities an equal opportunity to benefit from all of their programs, services, and activities (e.g., public education, employment, transportation, recreation, health care, social services, courts, voting, and town meetings).

State and local governments are also required to follow specific architectural standards in the new construction and alteration of their buildings. They also must relocate programs or otherwise provide access in inaccessible older buildings and communicate effectively with people who have hearing, vision, or speech disabilities. Public entities are not required to take actions that would result in undue financial and administrative burdens. They are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided.

How to File Complaints

The Rehabilitation Act prohibits discrimination based on disability in programs conducted by federal agencies, including programs receiving federal funds and in federal employment. In determining employment discrimination, the Rehabilitation Act uses the same standards as Title I of ADA.

Section 121 of the Rehabilitation Act authorizes the RSA to make grants to tribes for the purpose of vocational rehabilitation services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law. However, this agreement may not amount to a waiver of sovereign immunity. Sovereign immunity would prevent private parties from seeking redress in federal or state court. However,

sovereign immunity may not protect tribes from the Federal Government enforcing disability legislation. For nontribal businesses and services, federal law still applies.

Charges of employment discrimination on the basis of disability may be filed at any U.S. Equal Employment Opportunity Commission (EEOC) field office. Field offices are located in 50 cities throughout the United States and are listed in most telephone directories under "U.S. Government." For the appropriate EEOC field office in your geographic area, contact

Phone: (800) 669-4000
TTY/TDD: (800) 669-6820
Web site: www.eeoc.gov

Publications and information on EEOC-enforced laws may be obtained by calling
Phone: (800) 669-3362
TTY/TDD: (800) 800-3302

Information on how to accommodate a specific individual with a disability is available through the Job Accommodation Network.

Complaints of Title II violations may be filed with DOJ within 180 days of the date of discrimination. In certain situations, cases may be referred to a mediation program sponsored by the Department. The Department may bring a lawsuit when it has investigated a matter and has been unable to resolve violations. For more information, contact

Disability Rights Section; Civil Rights Division; U.S. Department of Justice
PO Box 66738
Washington, DC 20035-6738
Phone: (800) 514-0301
TTY: (800) 514-0383
Web site: www.usdoj.gov/crt/ada/adahom1.htm

The NCD, in collaboration with the National Urban League, has prepared "A Guide to Disability Rights Laws," which provides a summary of federal civil rights laws that

ensure equal opportunity for people with disabilities. The guide is available on NCD's Web site at www.ncd.gov/newsroom/publications/disabilityrights.html.

Consumer Disability Resources

"During the period of October 1994 to January 1995, about one in three American Indians and Alaskan Natives aged 15 and over reported having a disability, and one in seven reported having a 'severe' disability" (CBAIP, 2002). These statistics raise serious concerns, considering a tribe's ability to provide adequate resources and services for tribal members and descendants with disabilities. High unemployment rates on reservations, which range from 33.5 percent to 52 percent, make it challenging for American Indians with disabilities to find employment (CBAIP, 2002).

According to a review of VR research related to American Indians, "...over half (54 percent) of the studies cited indicated that American Indians are an under served population due to cultural and socioeconomic barriers, which include geographic isolation, poverty, lack of transportation, language differences, and value differences" (CBAIP, 2002). Almost half the studies "cited the need to increase VR services to American Indians with disabling conditions" The unique cultural and geographical characteristics of many tribes present challenges when attempting to serve its members. "A survey of State VR administrators revealed that rehabilitation barriers experienced by reservation-based American Indians with disabilities include (a) cultural differences, (b) geographic isolation, and (c) lack of employment opportunities" (CBAIP, 2002).

In 1994, the American Indian Disability Legislation Project conducted a survey of 143 AI and AN tribes to obtain information on the accessibility of public buildings, availability of rehabilitation services, and tribal awareness of disability laws. Surveyed tribes were also asked to report on the frequency of disabling conditions. Among the conditions most frequently cited among tribes in the continental United States were diabetes (29 percent), emotional disabilities (22 percent), and learning disabilities (11 percent). Among tribes in Alaska, emotional disabilities (31.3 percent), learning disabilities (17 percent), and deafness or hardness of hearing (17 percent) were the most frequently reported disabling conditions (American Indian Disability Legislation Project, 2000).

American Indian Rehabilitation Research and Training Center (AIRRTC) analyses found that alcohol abuse or dependence was the most common cause of disability among AI/ANs represented in the 1997 RSA database. Approximately 11 percent of AI/AN clients had a major diagnosis of alcohol abuse compared with only 4 percent of White, nearly 6 percent of Black, and less than 2 percent of Asian clients. Although the prevalence did not vary substantially by race, learning disabilities were found to be the second most frequent major diagnosis (9 percent) among AI/AN clients represented in the RSA database (Schacht, Gahungu, White, LaPlante, and Menz, 2000).

Mental health problems, along with alcohol and substance abuse, present some of the greatest challenges to Indian communities. The following subsections provide general directions in seeking services for some of the more prevalent forms of disabilities in Indian country. Unfortunately, it was not possible to list all of the services made available for those seeking assistance with mental health and alcohol and substance abuse treatment.

Mental Health

> *According to a report of the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA), Native Americans are more likely to experience mental disorders than other racial and ethnic groups in the United States. "Of great concern is the high prevalence of depression, anxiety, substance abuse, violence, and suicide. Other common mental health problems of Native American individuals are psychosomatic symptoms and emotional problems resulting from disturbed interpersonal and family relationships"(SAMHSA, p. 11). According to SAMHSA, failure to address the "historic trauma" and culture of Native Americans in health care and other areas "will only add to the oppression experienced by Native Americans for decades"(ibid, pp. 11-12). Nonetheless, disentangling socioeconomic factors, cultural influences, civil rights issues, and the effect of race/ethnicity is difficult for any health condition, particularly mental health disorders.*
>
> *—Vernellia Randall (2001)*

The devastating effects of historic trauma on Indian communities have left a large population of Indian people with what seems like overwhelming obstacles to face in an attempt to improve their quality of life. Depression and anxiety, along with

psychosomatic illnesses, can create huge barriers to employment. The RSA specifically addresses this critical aspect of employability.

Many tribal mental health programs are beginning to understand the need and effectiveness of utilizing culturally appropriate approaches toward healing.

Where Can I Get Help? Some tribes support their own mental health services. These services may reflect the unique cultural background of the local tribal community. Many tribal mental health programs are beginning to understand the need for and effectiveness of utilizing culturally appropriate approaches toward healing. If your tribe does not support a mental health program, it would be advisable to contact your local county mental health service. Depending on your need and financial status, mental health services can be provided for free or on a sliding-fee scale that will fit your financial status.

Alcohol and Substance Abuse

> *In 1999, there were about 43,000 American Indian and Alaska Native admissions to publicly funded substance abuse treatment facilities. A higher proportion of American Indian/Alaska Native treatment admissions were female (35 percent) than among the total treatment population (30 percent). Among American Indians/ Alaska Natives, admissions for alcohol abuse declined by 11 percent between 1994 and 1999, while admissions for illicit drugs increased by 78 percent.*
>
> *—Office of Applied Studies, Substance Abuse and Mental Health Services Administration (2002)*

As a result of over 500 years of cultural oppression and a brutal colonization process, nations of Indian people have been affected emotionally and spiritually. Each successive generation is embroiled in the battle with alcohol and substance abuse; these substances are often used to deal with the intergenerational pain associated with oppression.

Section 706 of the Rehabilitation Act recognizes the disabling effects of alcohol and substance abuse in our society and thereby makes provisions for employment assistance (www.eeoc.gov/laws/rehab.html).

Where Can I Get Help? Many tribes offer alcohol and substance abuse program services to some degree. Some tribes may have extensive services while others may

BEST COPY AVAILABLE

have none. The first step is to check with your tribe to see if they offer any alcohol and substance abuse services. If your tribe provides vocational rehabilitation, this program would most likely have the information you will need.

Intervention may include inpatient treatment or outpatient treatment depending on the severity of abuse. Many treatment centers are beginning to utilize culturally appropriate approaches toward healing. If your tribe does not provide chemical dependency counseling or referral services, you may contact your local county agencies. There are many forms of payment, and each is unique to the person's circumstances. Indian Health Services may assist you in this respect. Most important, do not give up. The process can sometimes be quick while at other times frustrating.

- **In 1999, there were about 43,000 American Indian and Alaska Native admissions to publicly funded substance abuse treatment facilities.**
- **A higher proportion of American Indian/Alaska Native treatment admissions were female (35 percent) than among the total treatment population (30 percent).**
- **Among American Indians/Alaska Natives, admissions for alcohol abuse declined by 11 percent between 1994 and 1999, while admissions for illicit drugs increased by 78 percent.**

Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA)

Spinal Cord Injury

"Approximately 200,000 individuals in the United States have spinal cord injuries. Every year, approximately 10,000 people sustain new spinal cord injuries" (Paralyzed Veterans of America, 2002). Most of these people are injured in auto and sports accidents, falls, and industrial mishaps. An estimated 60 percent of these individuals are 30 years old or younger, and the majority of them are men. In Indian country it is much the same.

By nature, a spinal cord injury (SCI) has a very sudden impact on an individual, physically as well as emotionally and socially. It is normal to have questions about how your life will be affected. Remember, though, that many other people have experienced SCIs and have continued to lead happy and productive lives. In order to

BEST COPY AVAILABLE

do so, you must become an active participant in your recovery. The resources described in the following pages are just the tip of the iceberg. Many people and organizations are available to help (Paralyzed Veterans of America, 2002).

For More Information Contact:

National Rehabilitation Hospital
102 Irving Street, NW
Washington, DC 20010
Phone: (202) 877-1000
Web site: info@nrhrehab.org

The National Rehabilitation Hospital specializes in treating persons with physical disabilities caused by spinal cord and head injuries, stroke, arthritis, amputation, multiple sclerosis, post-polio syndrome, and other neurological and orthopedic conditions.

National Spinal Cord Injury Association
6701 Democracy Boulevard
Suite 300-9
Bethesda, MD 20817
Phone: (301) 588-6959
Fax: (301) 588-9414
Web site: www.spinalcord.org

The National Spinal Cord Injury Association is the nation's oldest and largest civilian organization dedicated to helping the hundreds of thousands of Americans coping with the results of spinal cord injury and disease.

Paralyzed Veterans of America
801 18th Street NW
Washington, DC 20006-3517
Phone: (800) 424-8200
Web site: www.pva.org/index.htm

The Paralyzed Veterans of America, a congressionally chartered veterans service organization founded in 1946, has developed a unique expertise on a wide variety of issues involving the special needs of our members—veterans of the armed forces who have experienced spinal cord injury or dysfunction.

Shepherd Spinal Cord Injury Center
2020 Peachtree Road NW
Atlanta, GA 30309-1402
Phone: (404) 352-2020 (Main)
E-mail: Webmaster@shepherd.org

Atlanta-based catastrophic care hospital treats people with spinal cord injuries, acquired brain injuries, multiple sclerosis, and other neuromuscular illnesses and urological problems.

Spina Bifida Association of America (SBAA)
4590 MacArthur Boulevard NW, Suite 250
Washington, DC 20007-4226
Phone: (800) 621-3141or (202) 944-3285
Fax: (202) 944-3295
E-mail: sbaa@sbaa.org

SBAA addresses the specific needs of infants, children, and adults with spina bifida, their families, and professionals who serve them. As the national representative of over 70 chapters, it provides information and referral services, publishes materials, funds research, provides training, and conducts individual and systems advocacy.

Spinal Cord Injury Information Network
E-mail: sciWeb@uab.edu

This service, based at the University of Alabama's Spinal Rehabilitation Center, provides information and resources for people with spinal cord injuries.

Traumatic Brain Injury

There are a variety of causes of traumatic brain injury (TBI) ranging from a sudden physical assault to shaken baby syndrome. It can affect individuals of all ages and the impact of the injury can range from mild concussion to coma or even death. Symptoms of a TBI are also varied. These may include headache, nausea, confusion or other cognitive problems, a change in personality, depression, irritability, and other emotional and behavioral problems. Some people may have seizures as a result of a TBI (NINDS, 2002).

The resources and organizations that follow offer information and services to individuals and family members of individuals who have experienced a TBI. As in the previous case, more resources are available, but this is a starting point.

For More Information Contact:

Acoustic Neuroma Association
600 Peachtree Parkway, Suite 108
Cumming, GA 30041
Phone: (770) 205-8211
Fax: (770) 205-0239
E-mail: anausa@aol.com
Web site: www.anausa.org

Brain Injury Association
105 North Alfred Street
Alexandria, VA 22314
Phone: (703) 236-6000; (800) 444-6443
Fax: (703) 236-6001
E-mail: publicrelations@biausa.org
Web site: www.biausa.org

Brain Trauma Foundation
523 East 72nd Street, 8th Floor
New York, NY 10021
Phone: (212) 772-0608
Fax: (212) 772-0357
E-mail: info@braintrauma.org
Web site: www.braintrauma.org

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
Phone: (415) 434-3388; (800) 445-8106
Fax: (415) 434-3508
E-mail: info@caregiver.org
Web site: www.caregiver.org

National Rehabilitation Information Center (NARIC)
4200 Forbes Boulevard, Suite 202
Lanham, MD 20706-4829
Phone: (301) 562-2400; (800) 346-2742
Fax: (301) 562-2401
Web site: www.naric.com

National Stroke Association
9707 East Easter Lane
Englewood, CO 80112-3747
Phone: (303) 649-9299; (800) STROKES (787-6537)
Fax: (303) 649-1328
Web site: www.stroke.org

National Institute on Disability and Rehabilitation Research (NIDRR)
600 Independence Avenue SW
Washington, DC 20013-1492
Phone: (202) 205-8134
Web site: www.ed.gov/offices/OSERS/NIDRR

Tribal VR Program Resources

The organizations that follow offer resources, training, and technical assistance for individuals, tribes, and organizations planning to develop, support, and sustain VR programs.

Office of Special Education and Rehabilitative Services (Region X)
Department of Education
Rehabilitation Services Administration
915 2nd Avenue, Room 2848
Seattle, WA 98174
Phone: (206) 220-7847
Fax: (206) 220-7842
Web site: www.ed.gov

The Department of Education, Special Education, and Rehabilitation Services provides mentoring and oversight to programs funded in Region X as well as to tribal programs on a national basis. Regional responsibilities include VR agencies in the states of Oregon, Washington, Idaho, and Alaska. In addition, staff provides oversight, mentoring, and technical assistance to tribal VR programs across the country (there are only 69 VR programs yet more than 560 federally recognized tribes). American Indian rehabilitation programs function comparably to the state VR agencies except their services are provided to members of tribes who have disabilities and live on or near a reservation. The Region X Rehabilitation Services program has a rehabilitation services specialist with life experiences that provide intimate knowledge of tribal communities and tribal governments as well as federal and tribal barriers, which is particularly helpful for American Indian people in need of services.

American Indian Rehabilitation Research and Training Center
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86011-5630
Phone: (928) 523-4791
Fax: (928) 523-9127
TDD: (928) 523-1695
Web site: www.nau.edu/ihd/airrtc

The mission of AIRRTC is to improve the quality of life for American Indians and Alaska Natives with disabilities through the conduct of research and training that will result in culturally appropriate and responsive rehabilitation services; to improve employment outcomes and facilitate access to services for American Indians and Alaska Natives with disabilities; and to increase the participation of American Indians and Alaska Natives in the design and delivery of rehabilitation services for employment outcomes.

Certain basic principles represent the philosophy of AIRRTC and the guidelines by which AIRRTC will operate over the next five years. These principles are the result of AIRRTC's long-term involvement with American Indian rehabilitation and are consistent with the policies of RSA and the National Institute on Disability and Rehabilitation Research (NIDRR) and legislation such as the Rehabilitation Act, as amended.

Consortium of Administrators for Native American Rehabilitation
AIRRTC/CANAR Training and Technical Assistance Activities
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86011-5630
Phone: (928) 523-4791
Fax: (928) 523-9127
TDD: (928) 523-1695
Web site: www.nau.edu/ihd/airrtc

After the passage of the Rehabilitation Act Amendment of 1992, considerable actions were taken to enhance cultural competence in rehabilitation service delivery, increase outreach and services to persons with disabilities from diverse populations, and develop recruitment strategies of persons from diverse backgrounds to work in areas of rehabilitation. As a result of discussion and subsequent legislation, on January 22, 1993, the Consortia of Administrators for Native American Rehabilitation (CANAR) was established; it functions as a national platform for advocating the needs for effective rehabilitation service delivery for American Indians and Alaska Natives with disabilities who reside on or near federal or state reservations, Alaska Native villages, rancheros, and pueblos. CANAR addresses the concerns, abilities, capabilities, and informed choice of AI/AN consumers, so that they may prepare for and engage in gainful employment, including self-employment, telecommuting, and business ownership. CANAR continues to form collaborative working relationships with AIRRTC, state rehabilitation agencies, Regional Rehabilitation Continuing Education Programs (RRCEPs), tribal health and social service programs, capacity building projects, and federal service agencies such as the U.S. Department of Education and U.S. Department of Labor (Northern Arizona University, 2002).

Capacity Building for American Indians Project
American Indian Rehabilitation Research and Training Center
Capacity Building for American Indians Project
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86011-5630

Phone: (928) 523-4801
TTY: (928) 523-1695
Fax: (928) 523-9127
Web site: www.nau.edu/ihd/CBAIP

The AIRRTC Capacity Building for American Indians Project (CBAIP) is housed at the Institute for Human Development on the campus of Northern Arizona University. The mission of CBAIP is to enhance the capacity building and increase participation of American Indians and Alaska Natives in competition for discretionary rehabilitation grants, contracts, and cooperative agreements under Titles I through VIII of the Rehabilitation Act of 1973, as amended.

Many American Indians and Alaska Natives who are eligible to compete for discretionary rehabilitation grants, contracts, and cooperative agreements funded under the Rehabilitation Act of 1973, as amended, are not aware of these funding opportunities, or have limited knowledge regarding grant proposal development and the VR system. By the very nature of CBAIP, funded under the Capacity Building for Traditionally Underserved Populations Program, the target population of the Project includes traditionally under-represented groups: American Indians, Alaska Natives, minority entity representatives, and American Indians and Alaska Natives with disabilities. CBAIP ensures equal access and treatment for eligible project participants who are members of groups that have traditionally been under-represented.

National Rehabilitation Association
633 South Washington Street
Alexandria, VA 22314
Phone: (703) 836-0850
Fax: (703) 836-0848
TDD: (703) 836-0849
E-mail: info@nationarehab.org

Not long after Congress passed the National Rehabilitation Act of 1920, the National Rehabilitation Association (NRA) began its commitment to persons with disabilities. The NRA is the oldest and strongest advocate for the rights of persons with disabilities. Its mission is to provide advocacy, awareness, and career advancement for professionals in the fields of rehabilitation. Members of the NRA include rehab

counselors; physical, speech, and occupational therapists; job trainers; consultants; independent living instructors; and other professionals involved in the advocacy of programs and services for people with disabilities.

Seven core values provide the foundation for NRA services and programs:

1. All people
2. Professions in rehabilitation
3. Visionary leadership
4. Responsible resource management
5. Advocacy
6. Personal and professional enrichment
7. Relationships built on trust and integrity

In keeping with this commitment, the NRA has contributed and supported legislation such as the Rehabilitation Act of 1973 and subsequent reauthorizations, TJTC, the Job Training Partnership Act, and ADA. The association's prominence and longevity are recognized by our nation's leaders and give our members a vital role in shaping rehabilitation policy.

National Association of Multicultural Rehabilitation Concerns
633 South Washington Street
Alexandria, VA 22314
Phone: (703) 836-0850
Fax: (703) 836-0848
Web site: www.nationalrehab.org

The National Association of Multicultural Rehabilitation Concerns is a progressive association of individuals whose goal is to effect positive change and create opportunities for multicultural populations in the field of rehabilitation. Its philosophy is action-oriented and incorporates the following goals:

- To provide professional seminars, workshops, and training that focus on cultural diversity in rehabilitation and enhanced service delivery to multicultural persons with disabilities.
- To advocate, propose, and support legislation that addresses the needs of multicultural persons with disabilities and their communities.

- To encourage and recruit people of color to enter the field of rehabilitation.
- To provide current information on issues at the national, state, and local levels.
- To educate the multicultural community on services available to persons with disabilities and their families.

References

American Indian Disability Legislation Project, Research and Training Center on Rural Rehabilitation. (January 2000). Montana University Rural Institute on Disabilities.

Capacity Building for American Indians Project (CBAIP). (2002). Retrieved October 3, 2002, from www.nau.edu/ihd/CBAIP/needfor.html.

Center for Psychiatric Rehabilitation, Boston University. (1997). Retrieved December 12, 2002, from www.bu.edu/cpr/reasaccom/whatis-psych.html.

Clay, J. (1992). A profile of independent living services for American Indians with disabilities living on reservations. Missoula: University of Montana Rural Institute.

Department of Counseling, Human and Organizational Studies, George Washington University. (2002). Introduction to the Field of Rehabilitation Counseling. (2002). Retrieved December 22, 2002, from www.gwu.edu/~chaos/rehab/Rc_def.htm.

Minnesota Workforce Center. (2002). Vocational rehabilitation services. Retrieved December 30, 2002, from www.mnworkforcecenter.org/rehab/vr/definition.htm.

National Institute of Neurological Disorders and Stroke (NINDS). (2002). Traumatic brain injury information page. Retrieved January 6, 2002, from www.ninds.nih.gov/index.htm.

Northern Arizona University. (2002). Consortia of administrators for Native American rehabilitation. Retrieved October 3, 2002, from www.nau.edu/~ihd/CANAR/history.html.

Office of Applied Studies, Substance Abuse and Mental Health Services Administration (SAMHSA). (February 1, 2002). Dasis Report: American Indian and Alaska Natives in Substance Abuse Treatment: 1999. Washington, DC: SAMHSA.

Office for Students with Disabilities. (1997). Portland Community College. Retrieved October 3, 2002, from http://spot.pcc.edu/osd/504.htm#protected

Paralyzed Veterans of America. (2002). Retrieved December 16, 2002, from www.pva.org/NEWPVASITE/publications/onlinepubs.htm.

Randall, Vernellia R. (2001). Profile of Indian/Eskimo Communities, Chapter 2: Background: Disparity, Discrimination and Diversity in Health Care; Volume I, The Role of Governmental and Private Health Care Programs and Initiatives, The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring

Equality, Vol. I. (September 1999). Washington, DC: U.S. Commission on Civil Rights. Retrieved December 27, 2002 from http://academic.udayton.edu/health/08civilrights/01-02-13ProfileNative.htm.

Schacht, R., A. Gahungu, M. White, M. LaPlante, and F. Menz. (September 2000). An Analysis of Disability and Employment Outcome Data for American Indians and Alaska Natives. American Indian Rehabilitation Research and Training Center.

Social Security Administration. (2002). Fact Sheet: Effect of the Ticket to Work Program on the Use of Alternative Participants to Provide Vocational Rehabilitation Services to People with Disabilities. Retrieved December 2002 from www.ssa.gov/work/Service Providers/altpartprogfactsheet.html.

U.S. Department of Education (U.S. ED) Rehabilitation Services Administration. (2002). About RSA. Retrieved October 3, 2002, from www.ed.gov/offices/OSERS/RSA/About.

U.S. Department of Justice, Civil Rights Division, Disability Rights Section. (August 2001). A guide to disability rights laws. Retrieved September 27, 2002, from www.usdoj.gov/crt/ada/cguide.htm.

U.S. Department of Labor On-line. (2002). JAN's Web site portal for individuals. Retrieved October 3, 2002, from www.jan.wvu.edu

Assistive Technology

BEST COPY AVAILABLE

Danny Lucero

"The unique challenges deaf native people have in Indian Country are the inadequate services to meet their needs. Technology can give them the independence and self-esteem they need—whether it's TTY and phone accommodation, pagers, computers, or captioned media for education and entertainment."

BEST COPY AVAILABLE

Assistive Technology

Background

Assistive technology is simple or complex technology enabling individuals with disabilities to live more independently, productively, and enjoyably. Assistive technology increases one's ability to learn, work, compete, and interact with others (Washington Assistive Technology Alliance, 2002).

Assistive technology products can improve and strengthen physical or mental functioning, help overcome a disability, assist in preventing the worsening of a condition, improve learning capacity, and act as a replacement for missing limbs. These products may include communication aids, computer access aids, daily living aids, education and learning aids, home and work environment aids, hearing and listening aids, mobility and transportation aids, seating and positioning aids, vision and reading aids, recreation and leisure aids, prosthetics, orthotics, and ergonomic equipment (Rehabtool.com, 2002).

Assistive technology services help to support individuals with disabilities and their caregivers in selecting, acquiring, and/or using adaptive devices, which may include functional evaluations, device training, product demonstration, and the purchasing and leasing of equipment (Rehabtool.com, 2002). The Washington Assistive Technology Alliance provides the following definitions to help one understand the categories and types of assistive technology available for people with disabilities.

Model Approaches

In the United States, two Indian organizations are providing assistive technology devices and services specifically to Native Americans. Each of the programs that

Category	Types of Assistive Technology
Aids for Daily Living	Self-help aids for use in activities such as eating, bathing, cooking, dressing, toileting, home maintenance, etc.
Augmentative or Alternative Communication (AAC)	Electronic and nonelectronic devices that provide a means for expressive and receptive communication for persons with limited or no speech.
Aids for Deaf or Hard of Hearing	Aids for specific populations including assistive listening devices (infrared, FM loop systems), hearing aids, TTYs, visual and tactile alerting systems, etc.
Aids for Blind or Low Vision	Aids for specific populations including magnifiers, Braille or speech output devices, large print screens, closed circuit television for magnifying documents, etc.
Computer Access	Input and output devices (voice, Braille), alternate access aids (headsticks, light pointers), modified or alternate keyboards, switches, special software, etc., that enable persons with disabilities to use a computer. This category includes speech recognition software.
Environmental Control Systems	Primarily electronic systems that enable someone with limited mobility to control various appliances, electronic aids, security systems, etc., in their room, home, or other surroundings.
Home/Worksite Modifications	Structural adaptations or fabrications in the home, worksite, or other area (ramps, lifts, bathroom changes) that remove or reduce physical barriers for an individual with a disability.

BEST COPY AVAILABLE

Category	Types of Assistive Technology
Prosthetics and Orthotics	Replacement, substitution, or augmentation of missing or malfunctioning body parts with artificial limbs or other orthotic aids (splints, braces, etc.). There are also prosthetics to assist with cognitive limitations or deficits, including audiotapes or pagers (that function as prompts or reminders).
Seating and Positioning	Accommodations to a wheelchair or other seating system to provide greater body stability, trunk/ head support and an upright posture, and reduction of pressure on the skin surface (cushions, contour seats, lumbar).
Service Animals	The Americans with Disabilities Act defines a service animal as any guide dog (for individuals who are blind or have low vision), signal dog (for individuals who are deaf or hard of hearing), or other animals individually trained to provide assistance to an individual with a disability.
Wheelchairs/Mobility Aids	Manual and electric wheelchairs, mobile bases for custom chairs, walkers, three-wheel scooters, and other utility vehicles for increasing personal mobility.
Vehicle Modifications	Adaptive driving aids, hand controls, wheelchair and other lifts, modified vans, or other motor vehicles used for personal transportation.

follow exemplifies unique approaches to providing the core independent living services (individual and systems advocacy, peer counseling, information and referral, and independent living skills training) as well as additional services designed to meet the needs of the Indian communities it serves.

BEST COPY AVAILABLE

ASSIST! to Independence
Regional Resource Center for Assistive Technology
PO Box 4133
Tuba City, AZ 86045
Phone: (928) 283-6261; (888) 848-1449
Voice/TTY: (928) 283-6672
Fax: (928) 283-6284
E-mail: assist@cybertrails.com
Web site: www.assisttoindependence.org
Mike Blatchford, Executive Director

ASSIST! to Independence is a community-based nonprofit agency that was established by and for people with disabilities and chronic health conditions to help fill some of the gaps in service delivery. The agency serves as a consumer-driven community action program to facilitate general awareness of disability-related issues, community access, education, information sharing, assistive technology access, advocacy, and independent living that is relevant and culturally appropriate for American Indians. ASSIST! currently serves as the umbrella organization for five major programs: (1) The Center for Independent Living; (2) The Regional Resource Center for Assistive Technology; (3) The Special Needs Toy Lending Library; (4) The Functional Assessment Clinic; and (5) The Sensory Integration Program. The organization is located in the western part of the Navajo Reservation in Tuba City, Arizona, and its programs provide services primarily to the Navajo, Hopi, and Southern Paiute Reservations; however, anyone needing information and assistance in the northern part of the state is welcome to request services or information (ASSIST!, 2002a).

ASSIST! operates the Technology Resource Center, providing access to both low-tech and high-tech devices for people of all ages and varying abilities. Opportunities for hands-on exploration allow individuals to make more informed choices about the technology interventions that will work best for them. The ability to borrow a device to "try out" in the appropriate setting also provides greater opportunity for proper device selection and success. Most devices found in the Technology Resource Center are available for short- or long-term loan (ASSIST!, 2002b).

The Technology Resource Center also maintains an inventory of school-based assistive technology through a collaborative partnership with Southwest Human Development.

This technology is available for professionals working within school districts who need access to assistive devices for evaluation purposes (ASSIST!, 2002b).

The following services are provided through the Center for Assistive Technology:

- Equipment demonstration
- Short-term or long-term assistive technology equipment loans
- Training and education
- Information and referral
- Advocacy
- Technical assistance
- Comprehensive evaluations and assessments

In addition, the Resource Center participates as a member of the Navajo Nation Assistive Technology Consortium, which is actively working to develop the availability of more assistive technology resources on or near the Navajo Nation (ASSIST!, 2002b).

Native American Advocacy Project (NAAP)
Tiwahe Access (Family Access) Program
PO Box 527
208 South Main Street
Winner, SD 57580
Phone: (605) 842-3977; (800) 303-3975
TTY: (605) 842-3977
Fax: (605) 842-3983
E-mail: admin@sdnaap.org
Web site: www.sdnaap.org
Marla Bull Bear, Executive Director

The mission of the Native American Advocacy Project is to empower members of the American Indian Oyate in South Dakota who have developmental, physical, mental, and/or neurobiological disabilities to actualize their potential. NAAP provides education, training, advocacy, support, independent living skills, and referrals to them and to their Tiospaye. NAAP is a statewide, nonprofit, consumer and family membership organization for persons residing on and off lands of the nine tribal nations in South Dakota. NAAP is chartered with both the State of South Dakota and

the Rosebud Sioux Tribe (where NAAP's central office is located). NAAP is committed to providing support to the developing role of Native American consumers (persons with all types of disabilities) and their family members in system planning, decisionmaking, networking, advocacy, and service development for these populations. NAAP is also committed to being a cross-disability organization; they are inclusive of persons with all types of disabilities, not limiting efforts to only one or two disability groups but strengthening efforts on behalf of all persons with disabilities. This approach allows support to those persons with disabilities that have been under- or unrepresented in the disability movement (Native American Advocacy Project, 2002a).

NAAP operates the Tiwahe Access (Family Access) home modifications and adaptive devices program, providing ramps, bathroom modifications, kitchen modifications, and helpful tools to increase independence. This program provides home modifications and devices that are necessary for overcoming barriers that substantially limit a consumer's ability to function independently within a family or community and/or to obtain, maintain, or advance in employment. Some of the devices provided are reachers, doorbell indicators, eating utensils, personal hygiene and dressing aids, driving hand controls, environmental controls, and telecommunications adaptive devices. Home modifications include ramps, widened doorways, and bathroom and kitchen modifications (Native American Advocacy Project, 2002b).

Resources

On August 19, 1988, President Ronald Reagan signed into law the Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407), also known as the Tech Act. In 1994, the Tech Act (P.L. 103-218) was reauthorized by President Clinton. In 1998, it was reauthorized by the Assistive Technology Act (P.L. 105-394). This Act provides funding in the development of statewide, consumer-responsive information and training programs for people with disabilities (RESNA, 2002b). Indians with disabilities and providers may benefit by contacting their State Assistive Technology Program.

State Assistive Technology Financial Loan Programs and Other Loan Programs Serving Native Americans

Funded under Title III, Alternative Financing Programs, of the Assistive Technology Act of 1998, the State Assistive Technology Financial Loan Programs are administered by NIDRR. These and other assistive technology loan programs may be of assistance to Indians with disabilities in obtaining financial loans to purchase needed assistive technology. (RESNA, 2002).

General Assistive Technology Resources Available to Native Americans

Researching and learning about assistive technology products and services can become an overwhelming experience. Fortunately, private and public assistive technology resources are available that provide valuable information and guidance in an organized fashion.

Assistive Technology Advocacy

Advocacy provides a mechanism through which consumers and professionals can influence policy and program decisions affecting individuals with disabilities. Self-advocacy places value on individuals taking control of their lives and acting in their own best interest (see Advocating Change section). Self-advocacy requires an individual to be linked to information, understand complex rules, repeatedly communicate one's needs to an impersonal bureaucracy in an effective manner, and be persistent. Systems advocacy, in particular, seeks to improve policy responsiveness, increase resource sharing, and facilitate program access (Clay, 2002).

Systems advocacy may also present itself as an obstacle for individual Indians with disabilities due to the complex relationships between tribal governments, state governments, and the Federal Government, making targeted advocacy efforts difficult. However, systems advocacy has been critical to tribal governments in their goal to exercise self-determination and in the passage of the Self-Determination Act of 1976. Thus, through national organizations and an independent living center structure on a reservation, systems advocacy can work to make tribal governments more responsive

in addressing the needs and issues of tribal members having disabilities without putting these needs and issues above those of the community (Clay, 2002).

References

ASSIST! to Independence. (2002a). National Council on Independent Living best practices for consumer involvement in assistive technology programs Assistive Technology Survey – 2002. Retrieved September 26, 2002, from www.assisttoindependence.org/ati/survey.html.

ASSIST! to Independence. (2002b). The Regional Resource Center for Assistive Technology. Retrieved September 26, 2002, from www.assisttoindependence.org/ati/resource.html.

Clay, Julie Anna. (2002). Native American independent living. Retrieved October 7, 2002, from www.aidtac.org/NativeIL.htm.

DisabilityResources.org. (2002). Assistive technology—general. Retrieved September 25, 2002, from www.disabilityresources.org/AT-GENERAL.html.

Native American Advocacy Project. (2002a). Homepage. Retrieved September 26, 2002, from www.sdnaap.org.

Native American Advocacy Project. (2002b). Tiwahe Access. Retrieved September 26, 2002, from www.sdnaap.org/tiwahe.htm.

Neighborhood Legal Services, Inc. (2002a). Description of the National Advocacy Project. Retrieved September 27, 2002, from www.nls.org/natdisc.htm.

Neighborhood Legal Services, Inc. (2002b). Homepage. Retrieved September 27, 2002, from www.nls.org/index.html.

Neighborhood Legal Services, Inc. (2002c). PAAT Directory. Retrieved September 27, 2002, from www.nls.org/paatstat.htm.

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). (2002a). Alternative Financing Technical Assistance Project. Retrieved September 25, 2002, from www.resna.org/AFTAP/index.html.

Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). (2002b). Technical Assistance Project. Retrieved September 25, 2002, from www.resna.org/taproject/index.html.

Rehabtool.com. (2002). What's assistive technology? Retrieved September 23, 2002, from www.rehabtool.com/at.html.

Washington Assistive Technology Alliance. (2002). Assistive technology. Retrieved September 23, 2002, from http://it.wce.wwu.edu/necc97/poster1/Dolt/WebWhacker/WW684.html.

Housing & Facilities

BEST COPY AVAILABLE

Jessie Stewart

"Finding and sorting out choices is what's so important and why we're excited about the awareness this process and the toolkit will bring to Jessie's life." *Claudia Kauffman, Jessie's Mom*

BEST COPY AVAILABLE

Housing and Facilities

Background

It is estimated that of the 26 percent of American Indians and Alaska Natives living with a significant disability, as many as 94,000 individuals have a mobility or self-care limitation (Shuckahosee, 2000). In order to remain independent, many tribal members with disabilities living on tribal lands require support to make their homes, work environment, and other tribal facilities accessible and their active participation in tribal life possible. Though VR programs, with the cooperation of tribal governments, often make a good-faith effort to modify work environments on an as-needed basis so that they are suitable to individual needs, many challenges remain.

Barriers to Service

- Building/modification costs
- Limited program funding
- Administrative backlog for grants and protocol
- Limited awareness of universal design feasibility

The baseline housing conditions on tribal lands and limited funding for tribal housing programs may make meeting the needs of tribal members with disabilities seem insurmountable. According to a fact sheet prepared by the National American Indian Housing Council in 2000, between 21 and 69 percent of homes are overcrowded and have serious physical deficiencies compared with 5.9 percent nationally (AIDTAC, 2001). In addition, there is a "113-year staff backlog of title search requests at the Bureau of Indian Affairs that impedes lending and stalls desperately needed housing initiatives" (AIDTAC, 2001, p. 12).

BEST COPY AVAILABLE

The Basics of Universal Design

Universal design has also been called "life-span design," "inclusive design," and "trans-generational design." Its goal is to develop guidelines for housing construction that would create a livable, marketable environment for everyone regardless of ability, age, or size (City of San Antonio, 2002). Following are the five essential features of universal design that meet federal disability legislation requirements and the needs of individuals with a variety of physical disabilities (for further information on housing accommodations needed by individuals who are deaf, hard of hearing, or blind or have low vision, please see the Assistive Technology section of the Toolkit):

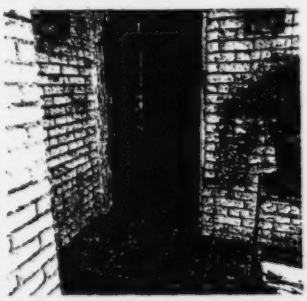
1. Provide one no-step entrance with beveled threshold. This may be at the front, side, or back of the house or garage entrance.
2. Make doorways throughout the home at least 32 inches wide; hallways at least 36 inches clear width.
3. Reinforce walls around the toilet, bathtub, and shower stall so that grab bars may be added later, if needed.
4. Install light switches and electrical controls no higher than 48 inches and electrical plugs no lower than 15 inches above the floor.
5. Install lever handles on exterior and interior doors and on sinks. (City of San Antonio, 2002, p. 1).

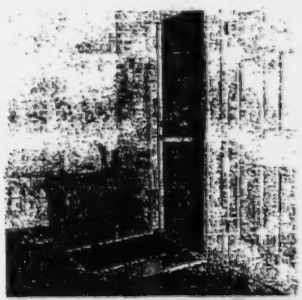
Figuring these features into builders' costs of new construction, the City of San Antonio Planning Department arrives at a total of $371 to $670 per house. Comparatively, later modification for necessary access would result in a cost of between $3,350 and $5,402 per house (City of San Antonio, 2002). While actual construction costs will vary by locality, savings from the integration of universal design at the time of construction versus later modification can be expected.

UNIVERSAL DESIGN

WHAT IS A VISITABLE HOME?

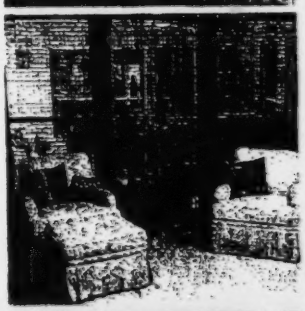
Basic access and visitability can be achieved simply and inexpensively by incorporating universal design features into all new construction. Some features and recommendations include:





One no-step entrance (may be at the front, side, back or garage entrance).

Open living spaces providing ample room for maneuvering and allowing good visibility throughout the house.

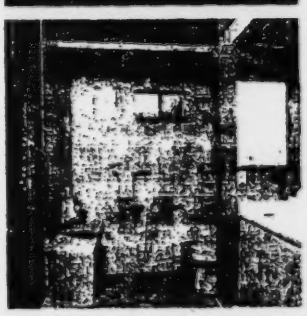


Doorways throughout the home at least 32 inches <u>clear width</u> with lever handles.

Hallways at least 36 inches <u>clear width.</u>

Appliance handles, electrical controls, and light switches no higher than 48 inches.

Reinforced walls near the bathtub and toilet so grab bars may be installed.



Prepared by the City of San Antonio
Department of Planning, Disability Access Office
Photographs by Kenny Braun courtesy of
The Enterprise Foundation

BEST COPY AVAILABLE

Assessing Service Needs

The first step to building a strong framework for services for people with disabilities is to know which services are currently available and which are not. The eight questions that follow were developed by the American Indian Disability Technical Assistance Center (AIDTAC) in order to begin this local assessment process.

1. What does your tribe or tribally designated housing entity (TDHE) do to provide accessible housing for members with disabilities?
2. Does your tribe or TDHE comply with Section 504 of the Rehabilitation Act?
3. Does your tribe or TDHE retrofit existing houses when someone needs a bathroom modified or ramp built?
4. What is your tribe or TDHE doing to make sure that people with disabilities have adequate accessible housing?
5. What cultural or traditional issues may be barriers to providing accessible housing for people with disabilities?
6. What are the major barriers to making more homes accessible on your reservation?
7. What resources does your tribe need in order to overcome these barriers?
8. What guidelines do you suggest for improving housing options for members with disabilities on your reservation? (AIDTAC, 2001, pp. 12-13).

These questions can be used within a talking circle or group format to bring together community members with diverse perspectives and come to a full understanding of the spectrum of needs within your specific community. From these shared experiences, new understanding and wisdom may grow to move the process forward.

When the time comes to develop a plan of action, the checklist developed by the City of San Antonio Department of Planning may be a useful starting point. It identifies eight steps to an "action plan outline for access compliance":

BEST COPY AVAILABLE

1. **Become Knowledgeable:** Prepare a good-faith plan for immediate barrier removal.
2. **Survey Existing Conditions:** Assemble a survey team including people with disabilities to assist in identifying barriers and developing solutions. You will need site and floor plans for making notes, and a tape measure.
3. **Summarize the Results:** List all identified barriers and indicate the actual dimension/conditions of each.
4. **Consider Possible Solutions:** Brainstorm ideas for barrier removal and determine probable costs for options. Decide which solutions best eliminate barriers at a reasonable cost. Consider practical alternatives.
5. **Prioritize Barrier Removal:** Priority One: Accessible entrances into the facility and path of travel to reach those entrances; Priority Two: Access to goods and services; Priority Three: Access to restrooms; Priority Four: Any other measures necessary to provide access
6. **Remove All Barriers Identified as "Readily Achievable":** A "Checklist for Readily Achievable Barrier Removal" is available through the City of San Antonio's Disability Access Office for use in completing a survey of potential architectural and communication barriers.
7. **Put a Good-Faith Action Plan in Place:** It is critical to demonstrate a good-faith effort that includes documentation of everything you have done and how you plan to address future compliance requirements.
8. **Utilize Dynamic Process for Continuing Accessibility:** Review your implementation plan each year to reevaluate whether more improvements have become readily achievable. (City of San Antonio, 2001)

Model Approaches

Partnerships between tribal programs working with the tribal council are essential to meeting the housing and facility accessibility needs of tribal members with disabilities. Partnerships with community organizations can also help to meet needs where tribal or federal funding comes up short. Even with limited resources, it is possible to make headway in prioritizing and responding to the needs of tribal

BEST COPY AVAILABLE

members with disabilities. The experience of the Oglala Lakota of the Pine Ridge Reservation is a case in point.

Pine Ridge "Quad Squad": Pine Ridge is home to the 17,775-member Oglala Lakota Tribe. The Pine Ridge Reservation includes seven counties with over 11,000 square miles and is situated in southwestern South Dakota on the Nebraska state line, about 50 miles east of the Wyoming border (Mni Sose, 2002). Jo White, director of the Pine Ridge "Quad Squad," which was formed in 1989, has continued the tradition of advocacy for individuals with disabilities on the Pine Ridge Reservation by coordinating services with the VR program and partnership activities with the tribal housing authority.

Challenge: With unemployment of nearly 84 percent (American Indian Relief Council, 2002), the Pine Ridge Reservation is the poorest area of the United States and faces significant economic challenges in achieving accessibility in housing and facilities.

Resolution: Despite this barrier, the tribal council, Oglala Sioux Tribal Housing Authority, and other tribal support services for individuals with disabilities led by the Quad Squad have worked together to increase accessibility on the reservation, identify individual needs, and develop a plan of response. Currently, the Housing Authority and the "Quad Squad" are working together to construct sidewalks and crossing lights to aid individuals who use wheelchairs or have another type of physical mobility disability.

How it happened: The needs of tribal members with disabilities are represented on the tribal housing board by an ex-officio member who is also a consumer. This board member is instrumental in ensuring that the needs of tribal members with disabilities are prioritized in the five-year plan and subsequent yearly block grant plans created under the authority of the Native American Housing Assistance and Self-Determination Act (NAHASDA). As a result, the Oglala have adopted the 5 percent rule of ADA, ensuring that 5 percent of all houses built are accessible. The Housing Authority maintains a waiting list of individuals with disabilities with accessibility needs. Currently, only six individuals are on this list, and for the first time, the Quad Squad has 10 ramps available for the immediate use of consumers; in the past, individuals have had to wait as long as one or two years for one to become available.

Partnerships with other community organizations, such as Native American Advocacy, and community church groups have helped to build this success as well.

Tips from the field: Following are some suggestions from the Quad Squad experience:

- Reach out to other organizations and tribal programs. Help is available, but one must find opportunities and build on them.
- Develop a voice in the tribal council and relevant boards. In order to make the needs of individuals with disabilities known, one needs a share of the voice of the tribal governance.

Making Plans a Reality

A number of organizations (Native and non-Native), federal and state agencies, and publications can help in the development of accessible housing and facility services for your community. Five frequently asked questions have been identified regarding accessible housing and facility services and the development of programs and related issues. Find your question, or one that is similar, in the list below.

Frequently Asked Questions

1. Whom do I contact first for help in making my home or work place accessible?
2. What legislation impacts housing for tribal members with disabilities, and how do I file a complaint if the laws are not being honored?
3. Where do I learn more about universal design?
4. Whom can I contact for technical assistance, training needs, networking opportunities, and information on housing?
5. What types of funding are available for tribal housing programs looking to create accessible facilities for tribal members, and how do I apply?

In the following pages, each question will be presented in bold with a short response and a recommendation of resources to contact for more information on the subject. Much of the contact information presented here was compiled with the assistance of the AIDTAC 2002 Resource Book (AIDTAC, 2002). If the information you are looking

BEST COPY AVAILABLE

for is not presented here, the Resource Book may provide further insight into your question. AIDTAC can be reached toll free at 1-866-4-AIDTAC or 1-866-424-3822, or via the Web at www.aidtac.org. The Internet sites for the agencies listed in this section may also prove useful in your own research.

Whom do I contact first for help in making my home or work place accessible?

Start by contacting your tribal housing authority and/or TDHE. The TDHE is the primary contact point for federal funds for housing and construction according to NAHASDA. The TDHE is designated by the tribe (and may double as the tribal housing authority or take membership from this group) to develop a five-year plan of action or overview of the direction the tribe will take in meeting its low-income housing needs as well as a yearly plan detailing the resources the tribe will use to meet these needs. The TDHE is then given funds allocated to the tribe in the form of a block grant. Each year approximately 540 tribes participate in this program for a total of approximately $640 million. A formula determines the actual amount allocated per tribe. The TDHE sets its own housing and construction priorities. From building ramps to building ILCs or for projects to modify existing buildings, the TDHE may use its resources as it best sees fit according to the needs of its low-income community (Jacobsen, 2002).

In many tribes, the Vocational Rehabilitation Office partners with the tribal housing authority and the tribal council to identify work place modification needs for tribal members with disabilities who train for work with tribal employers or with employers outside of tribal communities. As in the case of Pine Ridge, profiled in the Assistive Technology section, Vocational Rehabilitation Offices can serve as important advocates, assisting individuals with disabilities in raising the awareness and prioritization of their housing and accessibility needs. ILCs can also be an important source of information regarding housing and accessibility issues (see Independent Living section).

What legislation impacts housing for tribal members with disabilities and how do I file a complaint if the laws are not being honored?

The main legislation impacting housing for tribal members with disabilities consists of six acts. Five acts relate specifically to individuals with disabilities and provide for

accessibility in housing practices and procedures. The sixth reorganizes the U.S. Department of Housing and Urban Development (HUD) programs designed for Native American housing and provides another opportunity for individuals with disabilities to have their housing needs met.

Rehabilitation Act, Section 504: This piece of legislation prohibits discrimination on the basis of disability and requires that new construction and newly altered facilities built with federal funds be accessible. Each federal agency providing funds is responsible for enforcing the Act, and complaints must be directed to the federal agency with authorization for the particular project in question (Makoa, 2002).

The Architectural Barriers Act: This Act requires that buildings and facilities be accessible if, since 1968, they were "designed, built, or altered with certain federal funds, or if they are leased for occupancy by federal agencies" (Makoa, 2002). Accessibility standards cover things such as walks, ramps, curb ramps, entrances, elevators, and rest rooms. They are described in the Uniform Federal Accessibility Standards. Complaints may be filed with the Access Board (Makoa, 2002):

Office of Compliance and Enforcement
1331 F Street NW, Suite 1000
Washington, DC 20004-1111

Americans with Disabilities Act, Title II: ADA prohibits discrimination on the basis of disability in public accommodations in addition to its other charges (for a full description of the impact of ADA on tribal governments, please see the Federal Disability Law and Tribes section). ADA does not require a link to federal funds for application as the previous two acts do. The U.S. Department of Justice enforces Title III (Makoa, 2002).

Fair Housing Act: This law prohibits discrimination on the basis of disability in the sale, rental, or financing of housing. Also, it provides for certain architectural accessibility requirements in new, multifamily housing. Complaints may be filed with HUD (Makoa, 2002).

Native American Housing and Self-Determination Act: NAHASDA reorganizes the relationship between tribal governments and HUD, recognizing the right of self-

governance of American Indian tribes. As a result of this legislation, the block grant programs were consolidated, and tribally designated housing authorities in each eligible tribe are asked to make their own prioritization regarding how these funds are to be used (Jacobsen, 2002). Title VI of this Act authorizes a loan guarantee program designed to help ensure better access to private capital markets for Indian tribes.

Where do I learn more about universal design?

The City of San Antonio is an example of best practices in the area of community-oriented universal design. For those looking to learn more about these strategies and for technical guidance, the City of San Antonio is a great place to start. For a more technical perspective, HUD offers assistance on its Web site. Information can also be obtained by phone through HUD. Finally, the Uniform Federal Accessibility Standards provide the exact federal guidelines for accessibility.

Center for Universal Design
College of Design
North Carolina State University
50 Pullen Road, Brooks Hall, Room 104
Campus Box 8613
Raleigh, NC 27695-8613
Phone: (800) 647-6777; (919) 515-3082
Fax: (919) 515-7330
E-mail: cud@ncsu.edu

The Center for Universal Design is a national research, information, and technical assistance center that evaluates, develops, and promotes universal design in housing, public and commercial facilities, and related products.

U.S. Architectural and Transportation Barriers Compliance Board (Access Board)
Office of Technical and Information Services
1331 F Street NW, Suite 1000
Washington, DC 20004-1111
Documents

Phone: (800) 872-2253
TTY/TDD: (800) 993-2822
Electronic Bulletin Board Service: (202) 272-5448

This federal agency developed the ADA Accessibility Guidelines (ADAAG), which were adopted by the Department of Justice (DOJ) and the Department of Transportation (DOT) as enforceable standards and called the ADA Standards for Accessible Design. The Access Board provides technical assistance on the ADAAG regarding design and the removal of architectural, transportation, communication, and attitudinal barriers that affect persons with physical disabilities.

Whom can I contact for technical assistance, training needs, networking opportunities, and research information on housing?

Native American Indian Housing Council (NAIHC)
900 2nd Street NE, Suite 305
Washington, DC 20002
Phone: (202) 789-1754; (800) 284-9165
Fax: (202) 789-1758
Web site: http://naihc.indian.com/index.html

NAIHC is a national membership organization that promotes, supports, and upholds tribal housing agencies in their efforts to provide culturally relevant, decent, safe, sanitary, and affordable housing for Native people in American Indian communities and Alaska Native villages.

Center for Housing and New Community Economics (CHANCE)
Institute on Disability/UCE
University of New Hampshire
7 Leavitt Lane, Suite 101
Durham, NH 03824-3522
E-mail: drv@cisunix.unh.edu

CHANCE was established in March 2001. CHANCE's mission is to improve and increase access to integrated, affordable, and accessible housing coordinated with, but separate from, personal assistance and supportive services. CHANCE's purpose will be to offer

alternatives to approaches that segregate, congregate, and control people with disabilities. The IOD will work in partnership with American Disabled for Attendant Programs (ADAPT) in all aspects of the Center. ADAPT is a national organization that focuses on promoting services in the community for people with disabilities.

The Consortium for Citizens with Disabilities (CCD)
1730 K Street NW, Suite 1212
Washington, DC 20006
Phone: (202) 785-3388
Fax: (202) 467-4179
E-mail: Info@c-c-d.org

CCD is a coalition of national consumer, advocacy, provider, and professional organizations headquartered in Washington, D.C. Since 1973, the CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD does this by

- Identifying and researching public policy issues, developing testimony and policy recommendations, and encouraging innovative solutions to public policy concerns.
- Educating members of Congress in an effort to improve public policies and programs that foster independence, productivity, integration, and inclusion of people with disabilities.
- Encouraging people with disabilities and their families to advocate for themselves and coordinating grassroots efforts to support these advocacy efforts.

CCD has worked to achieve federal legislation and regulations that ensure that the 54 million children and adults with disabilities are fully integrated into mainstream society.

Fannie Mae Homepath Services
Phone: (800) 7FANNIE; (800) 732-6643
Web site: www.homepath.com/cgi-bin/WebObjects-4/HomePathWOF

Fannie Mae is the largest source of home mortgage funds in the United States. Homepath.com is a Web site designed to help consumers find mortgage information.

A Fannie Mae Foundation publication promotes economic understanding and personal financial literacy among Native people and teaches Native Americans financial skills that help them make informed financial decisions for themselves, their families, and their communities.

Housing Assistance Council (HAC)
National Office
1025 Vermont Avenue NW, Suite 606
Washington, DC 20005
Phone: (202) 842-8600
Fax: (202) 347-3441
E-mail: hac@ruralhome.org

Since 1971, this national nonprofit organization has worked to improve the availability of decent, affordable housing in rural areas of the United States by helping local organizations build affordable single- and multifamily homes for low-income people. HAC emphasizes local solutions, empowering the poor, reducing dependence, and using self-help strategies such as "sweat equity" construction. Special focus is on high-need groups and regions: Indian country, the Mississippi Delta, farmworkers, the Southwest border colonias, and Appalachia. If you have a general question or are not sure which office to contact, please contact the National Office at hac@ruralhome.org and HAC staff will determine who is best able to respond to you.

National Association of Home Builders (NAHB)
Research Center
400 Prince George's Boulevard
Upper Marlboro, MD 20774
Phone: (301) 249-4000; (800) 638-8556
Accessibility Concerns: (301) 430-6213; (301) 430-6234
Fax: (301) 430-6180

NAHB publishes *Residential Remodeling and Universal Design: Making Homes More Comfortable and Accessible* and houses the National Center for Seniors' Housing Research.

National Low Income Housing Coalition (NLIHC)
1012 14th Street NW, Suite 610
Washington, DC 20005
Phone: (202) 662-1530
Fax: (202) 393-1973
E-mail: info@nlihc.org
Web site: www.nlihc.org

Established in 1974, NLIHC is dedicated solely to ending America's affordable housing crisis. NLIHC educates, organizes, and advocates, ensuring decent, affordable housing within healthy neighborhoods for everyone. NLIHC provides up-to-date information, formulates policy, and educates the public on housing needs and the strategies for solutions.

Neighborhood Reinvestment Training Institute
1325 G Street NW, Suite 800
Washington, DC 20005
Phone: (202) 220-2454; (800) 438-5547
Fax: (202) 376-2168
E-mail: nrti@nw.org

The Neighborhood Reinvestment Training Institute is dedicated to providing the highest quality training to the staff and boards of organizations committed to improving the affordability of neighborhood housing, the vitality of neighborhood economies, and the quality of community life.

Rural Housing Service National Office
U.S. Department of Agriculture
Room 5037, South Building
14th Street and Independence Avenue SW
Washington, DC 20250
Phone: (202) 720-4323
Web site: www.rurdev.usda.gov/rhs/Feedback/feedback.htm

The U.S. Department of Agriculture (USDA) promotes rural development programs including housing assistance programs. The USDA supports programs in three main

areas: community facilities, single-family housing, and multifamily housing. The Web site will direct you to the appropriate state agency for grant or program applications and information.

What types of funding are available for tribal housing programs looking to create accessible facilities for tribal members, and how do I apply?

As Jo White, founding member of the Quad Squad in Pine Ridge, South Dakota, knows well, "there is a lot of great stuff to help you live independently, but it costs money; and getting money takes a lot of time" (White, 2002). Though Ms. White was speaking about assistive technology, the same can be said for housing and facility accessibility services. The following two agencies are where the funding hunt begins. However, innovation, openness to partnerships, and creative collaboration will lead to other sources that will help to meet the needs of not only low-income tribal members, but those struggling to make ends meet as well. The list of agencies and contacts described in the previous section may also be used to seek funding sources and programs.

U.S. Department of Housing and Urban Development
HUD Office of Public and Indian Housing;
HUD Office of Native American Programs
451 7th Street SW
Washington, DC 20410
Phone: (202) 708-1112
Fax: (202) 708-1455
Web site: www.hud.gov/groups/nativeamericans.cfm

HUD offers programs, assistance, and loan programs specifically for Native American tribes, organizations, and, sometimes, individuals. HUD offers information on basic homebuying, fair housing, and housing counseling. The HUD Office of Native American Programs offers grant assistance through four main programs; two are focused on tribal communities and two are focused on individuals. The Codetalk Web site administered by HUD is also an excellent resource for program information.

Bureau of Indian Affairs
Office of Public Affairs
1849 C Street, NW – MS-4542-MIB
Washington, DC 20240-0001
Phone: (202) 208-3711
Fax: (202) 501-1516
Web site: www.doi.gov

BIA's mission is to enhance the quality of life, to promote economic opportunity, and to protect and improve the trust assets of American Indians, Indian tribes, and Alaska Natives. BIA seeks to accomplish this by delivering quality services and maintaining government-to-government relationships within the spirit of Indian self-determination. The Bureau has limited funds available for road maintenance and low-income housing improvement programs. According to Bureau staff, the agency receives as many as 5,800 applicants for their low-income housing improvement grants. With a budget of $23 million per year, BIA is able to fill only approximately 500 requests; the waiting list is extensive (Hinkel, 2002). Currently, access to the Department of the Interior Web site is restricted in compliance with a court order.

References

American Indian Disability Technical Assistance Center (AIDTAC). (2002). *AIDTAC Resource Book*. Missoula: The University of Montana, Rural Institute on Disabilities.

American Indian Disability Technical Assistance Center (AIDTAC). (2001). *A Short Guide to Developing Disability Infrastructure on Reservations*. Missoula: The University of Montana, Rural Institute on Disabilities.

American Indian Relief Council (AIRC). (2002). Pine Ridge Reservation. Retrieved October 8, 2002, from www.airc.org/reservations/pineridge.html.

City of San Antonio Planning Department, Disability Access Office and Enterprise Foundation. (2001). Universal design 2001.

City of San Antonio Planning Department, Disability Access Office and Enterprise Foundation. Universal design. Flyer.

Hinkel, June. Bureau of Indian Affairs. (September 17, 2002). Telephone interview by Ara Walline.

Jacobsen, Donna, U.S. Department of Housing and Urban Development. (October 4, 2002). Telephone interview by Ara Walline.

Makoa. (2002). The Architectural Barriers Act and Other Access Laws. Retrieved October 4, 2002, from www.makoa.org/gov/g15.htm.

Mni Sose Intertribal Water Rights Coalition. (2002). Oglala Sioux Tribe Community Environmental Profile. Retrieved October 8, 2002, from www.mnisose.org/profiles/oglala.htm.

Shuckahosee, Robert, AIDTAC Rural Institute on Disabilities. (2000). Disability issues and Indian housing: Section 504 is a right! Missoula: University of Montana.

South Dakota Resource Directory. Retrieved October 23, 2002, from www.state.sd.us/dhs/drs/ADA/resourcedir/stateada.htm

U.S. Department of Justice. (2001). A Guide to Disability Rights.

White, Jo. (September 9, 2002). Telephone interview by Martina Whelshula.

Transportation

BEST COPY AVAILABLE

Cordia LaFontaine

"There are a lot of hidden disabilities and we need to make people aware of this...even if you don't look disabled, like with epilepsy, people can learn to realize this and accept us. I have my driver's license now and am capable of going places without having seizures or blackouts because of my surgery. Medicine alone didn't control these conditions. We need better awareness of help that's available to us, like surgery and pharmacy services."

BEST COPY AVAILABLE

Transportation

Background

The spectrum of transportation needs and barriers in Indian country is as diverse as the land itself. Among the 550 federally recognized tribes, the size, climate, and infrastructure of tribal lands vary, from the urban-centered Oneida Nation in Green Bay, Wisconsin, to the rural-based Cook-Inlet Tribe in the greater Anchorage area of Alaska. Correspondingly, services range from the dedicated community health representatives who provide primary transportation services for the Yakama Nation in Washington State to the dispatch-operated fleet of fully accessible vans operated by the Pueblo of the Zuni in Northwest New Mexico. In 1995, only 19 tribes had transportation programs funded by the Federal Transit Administration's Section 18 Federal Transit Grant for Non-Urban Areas (Community Transportation Association of America, 2002). Transportation resources and needs remain out of sync in many areas today.

Barriers to Service

- **Remoteness and isolation** (distance to services)
- **Limited public transportation services**
- **Lack of accessibility** (i.e., roads, providers, accommodations)
- **Economic hardship in private transportation ownership** (no money for car, insurance, maintenance, other transportation)
- **Driver's license** (limited drivers, suspension, inaccessibility)
- **Limited public transportation operation hours and service area** (no evening or weekend transportation)

Though each tribe is challenged to assess its own needs, match those to the services currently provided, and determine where the gaps in services lie, there are some

BEST COPY AVAILABLE

common struggles among individuals with disabilities across the nation. Transportation for tribal members with disabilities living on tribal lands is complicated by the high cost and in some cases physical impossibility of owning, adapting, insuring, and maintaining vehicles for personal use. Without a reliable tribal public transportation system to rely on, these individuals must rely on friends and family to meet their health, medical, employment, social, and household needs, or go without. An individual's level of independence is thus often determined to a greater extent by community resources, or lack of them, than by his/her own physical capabilities.

This section will provide tools for assessing your own tribal program, describe strategies that other tribes and service providers have used to overcome the barriers in their communities, and present resources and advocates that are available to assist in the development and implementation of your own action plan to improve transportation and access for people with disabilities in your community.

Assessing Service Needs

The first step to building a strong framework for services for people with disabilities is to know which services are currently available and which are not. The seven questions that follow were developed by AIDTAC in order to begin this assessment process. It is suggested that they be used within a talking circle or group format to bring together community members with diverse perspectives and to come to a full understanding of the spectrum of needs within your specific community. From these shared experiences, new understanding and wisdom may grow to move the process forward.

1. What transportation services are available on your reservation?
2. Are people with disabilities able to use these transportation services?
3. What is your tribe doing to make sure that people with disabilities have adequate transportation?
4. What are the cultural or traditional issues that should be addressed as barriers to transportation for people with disabilities?
5. What are the major barriers to making transportation on your reservation accessible to people with disabilities?
6. What resources does your tribe need in order to overcome these barriers?

7. What guidelines do you suggest for removing transportation barriers on your reservation? (AIDTAC, 2001, pp. 10-11)

Definitions

The following brief list of definitions developed by the National Transit Resource Center will assist you in navigating the resource information currently available as you look to grow and develop your existing transportation framework (Community Transportation Association of America, 2002). In this section, you will find descriptions of the variety of service structures currently used to meet the needs of individuals with disabilities. For a more complete glossary, the Web site of the National Transit Resource Center, Community Transportation Association of America, provides a good starting point (www.ctaa.org/ntrc/glossary.asp).

Accessibility: The extent to which facilities, including transit vehicles, are barrier-free and can be used by people who have disabilities, including wheelchair users.

Coordination: A cooperative arrangement between transportation providers and organizations needing transportation services. Coordination models can range in scope from shared use of facilities, training, or maintenance to integrated brokerages or consolidated transportation service providers.

Curb-to-Curb Service: A common designation for paratransit services. The transit vehicle picks up and discharges passengers at the curb or driveway in front of their home or destination. In curb-to-curb service the driver does not assist the passenger along walks or steps to the door of the home or other destination.

Demand-Response Service: The type of transit service where individual passengers can request transportation from a specific location to another specific location at a certain time (also called "dial-a-ride"). Transit vehicles providing demand-response service do not follow a fixed route but travel throughout the community transporting passengers according to their specific requests. These services usually, but not always, require advance reservations.

Deviated Fixed Route: This type of transit is a hybrid of fixed-route and demand-

response services. A bus or van passes along fixed stops and keeps to a timetable; however, the bus or van can deviate from its course between two stops to go to a specific location for a prescheduled request. Often used to provide accessibility to persons with disabilities.

Door-to-Door Services: A form of paratransit service that includes passenger assistance between the vehicle and the door of his or her home or other destination. A higher level of service than curb-to-curb, yet not as specialized as "door-through-door" service (where the driver actually provides assistance within the origin or destination).

Fixed Route: Transit services where vehicles run on regular, predesignated, prescheduled routes, with no deviation. Typically, fixed-route service is characterized by printed schedules or timetables, designated bus stops where passengers board and exit, and the use of larger transit vehicles.

Guaranteed Ride Home: Program that encourages employees to carpool, use transit, bike, or walk to work by guaranteeing them a ride home in case they cannot take the same mode home (e.g., if they need to work late or if an emergency occurs).

Medicaid: Also known as Medical Assistance, this is a health care program for low-income and other "medically needy" persons. It is jointly funded by state and federal governments. The Medicaid program pays for transportation to nonemergency medical appointments if the recipient has no other means to travel to the appointment.

Paratransit: Types of passenger transportation that are more flexible than conventional fixed-route transit but more structured than the use of private automobiles. Paratransit includes demand-response transportation services, subscription bus services, shared-ride taxis, car-pooling and vanpooling, and so on. Most often refers to wheelchair-accessible, demand-response van service.

Rideshare Program: A rideshare program facilitates the formation of carpools and vanpools, usually for work trips. A database is maintained for the ride times, origins, destinations, and driver/rider preferences of users and potential users. Those requesting to join an existing pool or looking for riders are matched by program staff

with other appropriate persons. In rural areas, a rideshare program is often used to coordinate Medicaid or volunteer transportation.

Service Route: Another hybrid between fixed-route and demand-response service. Service routes are established between targeted neighborhoods and service areas that riders want to reach. Similar to deviated fixed routes, service routes are characterized by flexibility and deviation from fixed-route intervals. However, while deviated fixed routes require advance reservations, service routes do not. A service route can include both regular, predetermined bus stops and/or allow riders to hail the vehicle and request a drop-off anywhere along the route.

Technical Assistance: Nonfinancial support to help accomplish program goals, such as training, consulting, research, or evaluation.

User-Side Subsidy: A transportation funding structure in which qualified users (usually economically disadvantaged persons) are able to purchase vouchers for transportation services at a portion of their worth. The users then may use the vouchers to purchase transportation from any participating provider. The vouchers are redeemed by the provider at full value and the provider is reimbursed by the funding agency for the full value.

Vanpool: A prearranged ridesharing service in which a number of people travel together on a regular basis in a van. Vanpools may be publicly operated, employer operated, individually owned, or leased.

Model Approaches

Recognizing that a weak transportation infrastructure may limit economic opportunities and pose a substantial barrier to accessing essential health and social services for individuals with disabilities as well as other tribal members, several tribes have developed model transportation systems. In developing these systems, tribes have tapped funding opportunities from a variety of state and federal sources. The end result has been transportation systems that are fully accessible to people with disabilities and that link these individuals to employment centers and health and human services programs.

Pueblo of the Zuni

The Pueblo of the Zuni is the largest of 19 pueblos in northwest New Mexico. It serves a population of 11,000 people and covers 1,000 square miles. Twelve years ago, Program Director Larry Alflen recognized transportation as one of the community's biggest barriers to service provision (Alflen, 2002). The profile that follows describes the work that has been completed so far.

Challenge: Situated 40 miles north of Gallup and 150 miles west of Albuquerque, the pueblo's remoteness and isolation caused considerable difficulty for tribal members to access services, particularly those tribal members with disabilities.

Resolution: Today, the Pueblo of the Zuni provides approximately 33,000 trips a year around the community, and up to 200 trips per day. The transportation program operates several 15-passenger vans (some with wheelchair lifts), is accessible to all tribal members, including those with disabilities, and is demand responsive (a dispatcher coordinates transportation requests). It also utilizes peer drivers to meet the needs of the community. In addition, several drivers and their dispatcher are graduates of the VR program.

How it happened: The program is funded through a number of grants: Sections 5311 and 5310 of the Transportation Act, otherwise known as the Small Urban and Rural Transportation Grant and the Capital Program for Elderly and Disabled Transportation; demonstration projects sponsored by the Association of Programs for Rural Independent Living (APRIL); a State of New Mexico vocational rehabilitation transportation grant; and endorsement by Medicaid for transportation reimbursement for services provided to individuals with disabilities. Most of these grants require reapplication every year. Developing strong relationships with agency grants administrators is key to understanding how to develop and sustain competitive proposals.

Tips from the field:

- Look at a variety of different opportunities to meet as many needs as possible.
- Develop strong relationships with agency grants administrators in order to understand how to develop competitive proposals.
- Explore overlaps in service needs and program opportunities.

Confederated Salish and Kootenai Tribes

The Flathead Reservation, home of the Confederated Salish and Kootenai Tribes, spans 1.5 million acres in seven communities. VR Program Director Arlene Templer has been working with program staff to develop transportation resources to connect tribal members to employment opportunities (Templer, 2002). The following profile, which is based on a telephone interview, depicts a program that continues to evolve.

Challenge: Remoteness and isolation are the primary barriers for this community as well. Many tribal members are as far as an hour away from the tribal complex and tribal health and human service offices where the majority of services are provided.

Resolution: Transportation needs were integrated into VR, elderly, and independent living grant proposals. In this way the resolution to the barrier became part of the process of strengthening existing services. The program uses a number of approaches and still recognizes that challenges remain in the implementation of the program even after it is developed and operational. The program uses a voucher system but sees that as a limited option because there are not many service providers. This limitation has led the program director to seek a more long-term resolution. Using accessible buses, vans, and cars, the program is developing a combination fixed-route dispatch service in collaboration with the Salish Kootenai College.

How it happened: The Confederated Salish and Kootenai Tribes responded to their transportation need by integrating services and seeking technical assistance through their extensive network of partnering agencies. By taking a two-pronged approach, they can offer temporary transportation services to supplement their VR, elderly services, and services for individuals with a disability while working to develop a more comprehensive service that is tailored to their community's specific need.

Tips from the field:

- Network with service providers, agencies offering grants, and technical assistance organizations in order to understand the service options available to your community.
- Consider integrating transportation services with the programs that transportation supports (e.g., vocational rehabilitation and job employment, education programs, elderly services, and disability services).

Other Programs

Several other tribes have developed strong transportation programs in their community. Among these are the Navajo Transit System in Arizona, the Choctaw Nation in Mississippi, the Chicksaw Nation Transportation System in Oklahoma, and the Shoshone and Arapaho Nation Transit System in Wyoming. Each of these programs operates fully accessible paratransit vans or vehicles that are ADA compliant. While empirical evidence has not been gathered regarding consumer satisfaction with these services, it is reasonable to believe that these systems have added another degree of independence for individuals with disabilities in these communities as they are more readily connected to employment and health and human services programs (Langwell and Sutton, 2002).

Making Plans a Reality

A number of organizations (Native and non-Native), federal and state agencies, and publications are available to help in the development of transportation services for your community. Six frequently asked questions have been identified regarding transportation services, the development of programs, and related issues. Find your question, or one that is similar, in the list below.

Frequently Asked Questions

1. How do you find out about transportation services in your area?
2. What do you do if there are no transportation services in your area?
3. How do you assess the transportation needs and develop a service network in your community?
4. How do you find funding to support transportation services and programs?
5. Who provides assistance with compliance?
6. What legislation on the horizon could impact transportation service funding? How do you keep informed about the impact of pending legislation on transportation in tribal communities?

BEST COPY AVAILABLE

In the following pages, each question will be presented in bold with a short response and a recommendation of resources to contact for more information on the subject. Much of the contact information presented here was compiled with the assistance of the AIDTAC 2002 Resource Book. If the information you are looking for is not presented here, the AIDTAC Resource Book may provide further insight into your question. AIDTAC can be reached toll free at 1-866-4-AIDTAC (1-866-424-3822), or on the Web at www.aidtac.org. The Internet sites for the agencies listed in this section may also prove useful in your own research.

1. How do you find out about transportation services in your area?

Begin by contacting your tribe. Transportation programs are most often affiliated with health care services or VR and employment services.

When greater distances are involved, a national database can assist you in locating and scheduling transportation and accommodation, whether it be air or ground transportation that you require. The information following provides a more extensive description of this service.

Project ACTION Accessible Traveler's Database
Phone: (202) 347-3066; (800) 659-6428
TTY/TDD: (202) 347-7385
Web site: www.projectaction.org/paWeb/index.htm

This database provides information about availability of local public transit systems (including private shuttle and taxi services) that are paratransit compatible. The database organizes service information by state and city, aiding travelers in planning and scheduling transportation at unfamiliar destinations as well as assisting individuals with disabilities in identifying existing services within their own communities. More specifically, the database includes seven types of service providers:

- Public urban and rural transit operators
- Accessible van rental companies
- Private bus/tour companies with accessible vehicles
- Accessible taxis
- Airport transportation

- Hotel-motel shuttles
- National 800 numbers (domestic airlines, Greyhound Intercity Services, Amtrak, companies with accessible car rental, and major hotel chains)

Each entry contains contact information for the service provider as well as hours of operation, paratransit fare, eligibility, service route, and advance reservation requirements. If you do not have access to the Internet, you may contact Easter Seals Project ACTION directly for assistance.

2. What do you do if there are no transportation services in your area?

If your community has not developed a transportation assistance program that is accessible to you or a family member with a disability, it does not mean that you or your friend or family member is alone in this need. Contacting your tribal health, education, or VR program will still be a good starting point. Using the tips in the Advocating Change section of this Toolkit and the resources of your tribe's program staff, identify and meet with other members of the community who may have similar transportation concerns.

This grassroots approach was incredibly successful for members of the Hopi Nation in Arizona. The early intervention program, special activity day, and newly formed VR program all grew out of the passionate commitment of a core group of parents and community members who identified a service need, educated themselves about the topic, formed a plan, and worked for change.

3. How do you assess the transportation needs and develop a service network in your community?

For help in assessing the service needs of your community and developing a program suited to those needs, a variety of organizations are available to guide you through the process. The following groups can direct you to resources, inform you about meetings and conferences on the topics you are interested in, and designate a technical liaison to work with you one-on-one in answering your questions. Groups specializing in independent living services, such as APRIL, may also provide assistance on transportation development (see Independent Living section).

American Indian Disability Technical Assistance Center (AIDTAC)
The University of Montana Rural Institute: Center of Excellence in Disability Education, Research and Services
52 Corbin Hall
Missoula, MT 59812-7056
Phone: (866) 4-AIDTAC; (866) 424-3822
Fax: (406) 243-2349
Web site: www.aidtac.org

AIDTAC is a Native American organization whose mission is to provide information and technical assistance to AI/AN tribes as they build their capacity to develop and implement culturally appropriate laws and policies, cross-cutting infrastructure, and direct program services for tribal members with disabilities. AIDTAC provides excellent information about funding opportunities, training seminars and workshops, and Internet research links. Eight staff members and five subcontractors are currently employed by the organization to provide assistance to consumers.

The National Transit Resource Center
Community Transportation Association of America (CTAA)
1341 G Street NW, 10th Floor
Washington, DC 20005
Phone: (202) 628-1480
Fax: (202) 737-9197
Web site: www.ctaa.org/ntrc/is_nativeamerican.asp
Contact: Chris Zeilinger; Phone: (202) 661-0217

The Resource Center recognizes the transportation needs and barriers in Indian country and offers specific resources for tribal governments and programs in addition to meeting its larger charge to support public and community transportation efforts serving community planners, transit providers, and on-the-move citizens with instructional briefs, studies, and reports, collected data, legislative facts, professional peer support, advice, and mobility assistance. In addition to the USDA program described below, the CTAA also works with the Labor and Transit Administrations to provide service support. Every January, it updates and publishes a joint funding and resource guide for tribal programs. Its publications include "Transportation in Indian Country: Getting Started," with worksheet guides to assist

program developers; "American Indian Transportation: Issues and Successful Models," with extensive program and funding information; and "Welfare Reform in Indian Country: Current Trends and Future Directions."

USDA Tribal Passenger Technical Assistance Program
National Transit Resource Center
Community Transportation Association of America
Phone: (202) 628-1480, ext. 119
Fax: (202) 737-9197
Web site: www.ctaa.org/ntrc/usda/projects/tpttap_brochure.asp

This program is designed to help tribal communities enhance economic growth and development by improving transportation services. It provides planning assistance for facility development, transit service improvements and expansion, new system start-up, policy and procedure development, marketing, transportation coordination, training, and public transit problem-solving activities. Federally recognized tribes are eligible to receive assistance. Tribes must complete and submit an application to CTAA for review, scoring, and ranking. Projects are initiated according to this approval process.

Easter Seals Project ACTION
(Accessible Community Transportation in Our Nation)
700 13th Street NW, Suite 200
Washington, DC 20005
Phone: (202) 347-3066; (800) 659-6428
TTY/TDD: (202) 347-7385
Fax: (202) 737-7914
E-mail: project_action@opa.easter-seals.org
Web site: www.projectaction.org

Funded through a cooperative agreement with the U.S. Department of Transportation and the Federal Transportation Administration, Easter Seals Project ACTION (ESPA) promotes cooperation between the transportation industry and the disability community to increase mobility for people with disabilities under ADA and beyond. Project ACTION offers various resources, as well as training and technical assistance, in an effort to make ADA work for everyone, every day. Congressionally mandated priority areas include transportation needs assessment of people with disabilities in

local communities; outreach and marketing strategies, training for transit providers and consumers with disabilities, and technology to eliminate barriers to transportation accessibility.

ESPA has created a solid outlet for information dissemination through the development of a resource center, clearinghouse, an 800 number, and Web site and participation in technical assistance conferences. All training curricula, manuals, models, and videotapes are available at no cost. Funding has been mandated for this project through 2003 under the Transportation Equity Act for the Twenty-first Century.

Transportation Research Board (TRB)
2001 Wisconsin Avenue NW, Green Building
Washington, DC 20007
Phone: (202) 334-2934
Fax: (202) 334-2003
Web site: http://trb.org

The TRB is a unit of the National Research Council, a private, nonprofit institution whose mission is to promote innovation and progress in transportation by stimulating and conducting research, facilitating the dissemination of information, and encouraging the implementation of research results. Cooperative research programs fund research projects that seek to answer transportation problems solicited by community programs—research ideas can be directed to this agency for consideration.The TRB is funding an ongoing research project entitled "Increasing Native American Participation in Programs and Services of the Federal Transit Administration." The TRB also hosts an annual conference on transportation issues that attracts as many as 8,000 professionals from throughout the United States and abroad.

U.S. Department of Transportation (DOT)
400 7th Street SW
Washington, DC 20590
Phone: (202) 366-4000
Web site: www.dot.gov

DOT oversees the formation of national transportation policy and promotes intermodal transportation. It administers the budget authority for a number of grant

programs accessible to AI/AN tribes. Several agencies under this authority such as the Federal Highway Administration also have Native American liaisons that work directly with tribes. Resources such as the toll-free Hotline to Assist Air Travelers with Disabilities (operated between the hours of 7 AM and 11 PM EST daily at 1-800-778-4838 or TTY 1-800-455-9880) have been implemented to fulfill the responsibility of DOT under ADA and other applicable legislation.

National Rural Transit Assistance Program (RTAP)
Federal Transit Administration
TransNet Program
Phone: (800) 527-8279

Current information on American Indian transportation issues and practices and how you can replicate them in your community is available via the TransNet service at the hotline above. This service will match you to a networker whose particular experience will be relevant (Shawn, 2002, p. 9).

In addition to this service, each state operates a rural transit assistance program to provide training, technical assistance, and resource information to transportation providers. The National Transit hotline may be accessed at 1-800-527-8279. It can provide you with a variety of information: answers to simple or complex questions, how to solve a transit problem, written materials, and referrals to peers with expertise in the start-up and operation of tribal transportation services (Shawn, 2002).

4. How do you find funding to support transportation services and programs?

According to the issue brief developed by the World Institute on Disability and excerpted by APRIL, in 1999, only 5 percent of transportation dollars were allocated to serve the 27 percent of the population living in rural America (including those living on tribal lands), a disproportionate number of which are disabled (Gonzales, Seekins, and Kasnitz, 1999). Clearly, identifying funding sources and completing a competitive application are challenges for many new and developing transportation systems in rural locations. Tribal programs are no exception.

Tribes with successful transportation programs, like those profiled above, develop a

budget through a combination of funding sources: grants from multiple agencies and organizations, tribal revenue, and creative collaborations. Funds can be made available to transportation programs through federal and state agencies or as a result of legislative authority. The legislation authorizing transportation for individuals with disabilities as well as the primary agencies providing funds to programs is described below. These descriptions can serve as leads for you to follow up with and identify funding sources specific to your unique program needs.

Laws Addressing Transportation Rights of Individuals with Disabilities

Many of these descriptions are based on the references provided by the NTRC Web site Glossary. Please visit www.ctaa.org/ntrc/glossary.asp for more information.

Americans with Disabilities Act (ADA): Passed by Congress in 1990, this Act mandates equal opportunities for persons with disabilities in the areas of employment, transportation, communications, and public accommodations. Under this Act, most transportation providers are obliged to purchase lift-equipped vehicles for their fixed-route services and must ensure system-wide accessibility of their demand-responsive services to persons with disabilities. Public transit providers also must supplement their fixed-route services with paratransit services for those persons unable to use fixed-route service because of their disability.

Transportation Act: Section 5310: The section of the Federal Transit Act that authorizes capital assistance to states for transportation programs that serve the elderly and people with disabilities. States distribute Section 5310 funds to local operators, in both rural and urban settings, who are either nonprofit organizations or the lead agencies in coordinated transportation programs.

Section 5311: The section of the Federal Transit Act that authorizes capital and operating assistance grants to public transit systems in areas with populations of less than 50,000.

Workforce Investment Act: This 1998 legislation consolidates the former Job Training Partnership Act and many other federal job training programs into state-managed block grants. This law also replaces Private Industry Councils with

Workforce Investment Boards. The Act authorizes the provision of supportive services (e.g., transportation) to assist participants receiving the other services and the provision of temporary income support to enable participants to remain in training.

Older Americans Act: First passed in 1965, this federal law established a network of services and programs for older people. This network provides supportive services, including transportation and nutrition services and works with public and private agencies that serve the needs of older individuals.

Transportation Equity Act for the Twenty-first Century (TEA-21): This 1998 legislation authorizes approximately $217 billion for highways, highway safety, and mass transportation until fiscal year 2003.

Intermodal Surface Transportation Efficiency Act of 1991 (ISTEA): Administered by the Federal Transit Administration, this Act is the principal source of federal financial assistance for public transportation. Additional DOT funds may be available through ISTEA's flexible funding provisions, which allow states to transfer federal highway funds to transit programs for capital projects. Many states have found ISTEA to be a valuable mechanism for acquiring additional vehicles and facilities for their rural transit activities, including some American Indian transit programs (Shawn, 2002).

Social Security Act, Title XIX: This section of the Social Security Act describes, among others, the eligibility determination and transportation services offered by Medicaid programs for individuals with disabilities and elderly individuals with low income (see Centers for Medicare & Medicaid Services contact information on following page).

Funding Sources for Programs

Federal Transit Administration (FTA)
400 7th Street SW
Washington, DC 20590
Phone: (202) 366-4043
Fax: (202) 366-3472
Web site: www.fta.dot.gov/office/regional

A component of the U.S. Department of Transportation that regulates and helps fund public transportation, FTA provides financial assistance for capital and operating costs and also sponsors research, training, technical assistance, and demonstration programs. FTA was created by the passage of the Urban Mass Transportation Act of 1964. In addition to the national office referenced above, 10 regional offices and 5 metro offices provide contact points.

Administration on Aging
330 Independence Avenue SW
Washington, DC 20201
Phone: (800) 677-1116 (Eldercare Locator: finds elder services in locality); (202) 619-7501 (National Aging Info Center: technical info and public inquiries); (202) 401-4541 (Office of Assistant Secretary for Aging: congressional and media inquiries)
Fax: (202) 260-1012
Web site: www.AOA.dhhs.gov

The Administration on Aging agency within the U.S. Department of Health and Human Services oversees the implementation of the Older Americans Act, which provides funds to meet the needs of American Indian elders. Services provided under Title VI include nutrition, information, and referral and transportation services. The Area Agency on Aging is the local entity that plans senior services and advocates for the elderly within their communities, administering provisions of the Older Americans Act on this level.

Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850
Phone: (410) 786-3000
Web site: www.hcfa.gov

Also known as Medical Assistance, this is a health care program for low-income and other "medically needy" persons. It is jointly funded by state and federal governments. The Medicaid program pays for transportation to nonemergency medical appointments if the recipient has no other means to travel to the appointment. Developing a local reimbursement relationship with the Medicaid program office can be an important strategy for tribes to build self-sustaining transportation systems.

Temporary Aid to Needy Families (TANF)
Administration for Children and Families
U.S. Department of Health and Human Services (HHS)
Division of Tribal Services
370 L'Enfant Promenade
Washington, DC 20447
Phone: (202) 401-9214
Web site: www.acf.dhhs.gov/programs/dts/rcontact.htm

Spurred on by the passage of the landmark welfare reform legislation—the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193)—TANF is a program of block grants to states to help them meet the needs of poor families. It replaces Aid to Families with Dependent Children, JOBS, Emergency Assistance, and some other preceding federal welfare programs. Because of TANF-imposed time limits, states trying to place TANF recipients in jobs as quickly as possible often use program funds to pay for transportation, child care, and removing other barriers to workforce participation.

Other sources of funding may include the following: Vocational rehabilitation grants; APRIL (has provided demonstration project funding for transportation projects in past); the Veterans Administration; the U.S. Department of Agriculture (agency with primary responsibility for rural economic and community development); HHS (funds a variety of human services transportation through the AOA, Head Start, Medicaid, and other programs); the Administration for Native Americans (another HHS agency with a limited amount of funding available for American Indian social and economic development activities, which can include transportation); and DOT (Shawn, 2002).

5. Who provides assistance with compliance?

When service obligations provided for by the legislation of the Federal Government are not met, certain departments field these concerns. Access to transportation services for individuals with disabilities has been established as a requirement under ADA as well as other legislation detailed above. The following contact points should be used when initial attempts to resolve a concern at the time and place of the experience are not successful.

The Access Board
1331 F Street NW, Suite 1000
Washington, DC 20004-1111
Phone: (202) 272-5434; (800) 872-2253
TTY/TDD: (202) 272-5449; (800) 993-2822
Fax: (202) 272-5447
E-mail: info@access-board.gov
Web site: www.access-board.gov

The Access Board is an independent federal agency devoted to clarifying standards and requirements to provide accessibility for people with disabilities. It operates with about 30 staff and a governing board of representatives from federal departments and public members appointed by the President. The Board has three key responsibilities: developing and maintaining accessibility requirements for the built environment, transit vehicles, telecommunications equipment, and electronic and information technology; providing technical assistance and training on these guidelines and standards; and enforcing accessibility standards for federally funded facilities.

6. What legislation on the horizon could impact transportation service funding? How do you keep informed about the impact of pending legislation on transportation in tribal communities?

Developing relationships with grant program administrators and working closely with state agencies and transportation organizations will go far in keeping you informed about legislation that may impact your transportation program. Because many applications are competitive and must be reapplied for annually, continuing to develop and evaluate your program, being responsive to your community's needs, and maintaining open communication lines with your grant administrators are all the more important. Maintaining a diverse funding portfolio will also help you to weather any unforeseen budget cutbacks.

By advocating at the state and federal levels through participation in boards, councils, associations, and related transportation organizations, you can also ensure that the needs of your community are understood by those who work to shape legislation and develop grant programs in the first place. Each year, there are opportunities to impact legislation and work for change. Sen. Max Baucus (D-Mont.)

and several of his colleagues recently introduced a bill entitled the Maximum Economic Growth for America through Rural, Elderly and Disabled Transit Investment Act (MEGA RED Act). This bill seeks to improve transit service in rural areas, including for the elderly and persons with disabilities. This bill also has provisions that would positively impact tribes operating transportation systems on tribal lands.

References

Alflen, Larry. (September 24, 2002). Telephone interview by Martina Whelshula.

American Indian Disability Technical Assistance Center (AIDTAC). (2002). *AIDTAC Resource Book.* Montana: The University of Montana, Rural Institute on Disabilities.

American Indian Disability Technical Assistance Center (AIDTAC). (2001). *A Short Guide to Developing Disability Infrastructure on Reservations.* Missoula, MT: The University of Montana, Rural Institute on Disabilities.

Community Transportation Association of America, National Transit Resource Center. (2002). Transportation in Indian country: Getting started. Edited by Intersoft Corporation. Retrieved October 1, 2002, from www.ctaa.org/ntrc/ctap/pubs/tribe.asp.

Gonzales, Linda, Tom Seekins, and Devva Kasnitz. (1999). Taking on rural transportation. Excerpt from *Issue Brief in Independent Living and Disability Policy,* 1(4). World Institute on Disability. Retrieved September 25, 2002, from http://april.umt.edu/Taking.htm.

Langwell, Kathy, and Janet Sutton. (2002). *People with Disabilities on Tribal Lands: Education, Health, Rehabilitation, and Independent Living.* Washington, DC: National Council on Disability.

National Transit Resource Center. (2002). Public and community transportation glossary. Edited by Intersoft Corporation. Retrieved September 30, 2002, from www.ctaa.org/ntrc/glossary.asp.

Shawn, Kelly. American Indian Transportation: Issues and Successful Models. *RTAP National Transit Resource Center, Technical Assistance Brief Number 14.* Edited by Intersoft Corporation. Washington, DC: Community Transportation Association of America. Retrieved October 1, 2002, from www.ctaa.org/ntrc/rtap/pubs/ta/am-ind.asp.

Templer, Arlene. (September 10, 2002). Telephone interview by Martina Whelshula.

Zeilinger, Chris. (September 24, 2002). Telephone interview by Ara Walline.

Key Elements of Promising Programs

BEST COPY AVAILABLE

Andrea Siow

"By getting the word out that people with disabilities are not helpless, we can create awareness and improve things. Everybody has his or her own unique gifts. It is up to us to find our path. We must show others and teach people to look beyond differences and find good in everyone."

Key Elements of Promising Programs

Background

Indian country embodies some of the most diverse cultures, communities, political structures, and natural environments the nation knows. Therefore, it stands to reason that each tribe addresses the unique circumstances of tribal members with disabilities in very different ways. The project task was to find those tribes in the nation that demonstrated leadership in creating awareness, developing programs, adopting tribal laws, and meeting the needs of its tribal members with disabilities. Leaders and advocates in the Indian country disability movement recommended tribes that best exemplified successful practices. Of the 16 tribes recommended, 10 were selected for follow-up interviews.

The interview questions addressed tribal government support through the development of disability laws, support services, major barriers for people with disabilities, access and barriers to health care, children with disabilities being treated differently, available employment services through the tribe, and what types of information or resources would be helpful to tribes. The responses by tribal programs were overwhelmingly positive, producing a wealth of information and wisdom.

Throughout the interviews, certain themes emerged that reached across each tribe. These themes appeared to be the key elements of success for their programs. This rich information is to be shared with all tribal communities desiring to improve their tribal community environment for members with disabilities. The following section summarizes key elements for these promising practices in tribal communities.

Leadership

In the course of interviewing the tribes, it became increasingly evident that the program took on the qualities and characteristics of its leadership. Common elements shared by each program director were as follows:

Passion

Each of the program directors demonstrated this trait in shared thoughts and action. Their passion was conveyed not only through descriptions of their program and the services delivered, but in the difficulties many programs transcended over time.

Perseverance

In the face of many challenges and obstacles, the program leaders' belief in their work helped individuals to keep moving and fighting for changes when the task seemed almost impossible.

Vision

Each program leader believed in the possibilities for change in their tribal communities and seemed to have mental pictures and plans demonstrated by the many unique and innovative approaches to addressing the huge gaps in services for tribal members with disabilities.

Commitment

The majority of program leaders had worked in their program for several years; they were determined to create change to improve the quality of life and services for tribal members with disabilities.

Change Agents

These program leaders pushed for creative and different ways of doing things that sometimes made them unpopular with others who favored the status quo.

Consistency

Program leaders who stayed with their programs for many years provided a sense of reliability, stability, and consistency. The element of consistency nurtured the slow

process of growth and occurred in ways that build upon the many lessons learned through the years.

Connection to Consumer

These program leaders strive to know their consumers despite some complex circumstances and multiple variables surrounding programs.

Agents of Hope

Many of the conditions surrounding the whole issue of disabilities in Indian country are severe enough to leave consumers and advocates feeling a sense of hopelessness. Some program leaders have described the bleak realities of tribal members with disabilities. In the face of some very real and despairing conditions, these program leaders try to embody a positive sense of hope, inspiring consumers to hang in there; change is coming.

Most program leaders will tell you that they hold only one part of the total effort needed to improve the quality of life for tribal members with disabilities. The leaders described the many people who have given so much to the success of the services. Humility was evident as these leaders expressed excitement in how segments of their tribal community fought long and hard for change that resulted in improvements. When they speak of success, they do not speak solely in terms of a personal success; rather, they speak of success in terms of a collective effort by other community members who have expressed their own passion in the work.

Leadership Characteristics

A program leader who embodies the qualities and characteristics of passion, perseverance, vision, commitment, change, consistency, and connection, and who is seen as an agent of hope, can influence the success of a program greatly.

Responsiveness to the Needs of the Consumer

Successful programs require staff to know their consumers well. This requires moving beyond the initial identification of consumer needs to the development of personal relationships with consumers in order to truly understand the realities experienced by

tribal members with disabilities. These programs tailor their services around the unique needs presented in each tribal community and around each consumer.

Innovation in Removing Barriers

"Necessity is the mother of invention" is a phrase that exemplifies the motivation behind many innovative programs throughout Indian country. The personal diligence and leadership of individuals with disabilities and/or their family members have helped to reshape tribal communities and create more awareness, break down barriers, and push for expanded services and advocacy. Through their advocacy, tribal programs have realigned programs to create seamless services and more comprehensive support.

Effective Collaboration

A key factor for a successful program rests in the program's ability to effectively collaborate between agencies, programs, and funding sources. Those programs whose staff have extensive knowledge and awareness of other programs and services were able to develop the most comprehensive and innovative programs. All 10 of these tribes have demonstrated how their creative collaborations increased the success of their programs in serving tribal members with disabilities.

Advocacy Strength

Advocacy is another key program success factor. Advocacy seems to be an inherent process of the work in Indian country. It is a primary source of support for tribal members with disabilities who don't know how to or can't advocate for themselves. Advocacy comes in many forms and is multidimensional. It is evident from the many voices of program leaders that it is essential to successfully serve people with disabilities.

Support from Tribal Leadership

Every tribal program included in this report noted that tribal leader support was an important factor in the success of the program. However, tribal leader support looked very different from tribe to tribe. Although not all tribes have laws protecting the rights of tribal members with disabilities, some have personnel policies and procedures, while other programs feel supported by their tribal leadership in some way.

Conclusion

Combinations of the elements identified from promising practices observed in existing programs seem to be aligned with comments by tribal leader Chief Joseph, Nez Perce: "The earth is the Mother of all people, and all people should have equal rights on it." In the development of local policies, processes, and programming to serve and protect the rights of tribal members with disabilities, the power of collaboration and overarching awareness of local tribal culture must be considered. Unless programs are culturally responsive, consumers will not patronize the services offered. Knowing the consumer through meaningful inclusion in planning and hiring and risking innovation in an attempt to design a program that fits consumer needs rather than making the consumer fit the program design are also critical for success. Combined support from tribal leadership, committed and culturally responsive program staff, and positive results for people with disabilities in Indian country can enhance their empowerment.

Advocating Change

BEST COPY AVAILABLE

David Miles

"We need to learn about the 'forgotten people,' respect them so they can learn to live with whatever their challenge is without going into denial and grief."

Advocating Change

Self-Advocacy

Considering the number of programs and services a person with disabilities interacts with on a day-to-day basis, success depends a great deal on your resolve. The maze of programs and services can and will be frustrating to understand and deal with. For the most part, it may not be possible to have an advocate present who understands your overall journey. In many cases, it may be just you. Self-advocacy can be a truly liberating and empowering experience while you seek to improve your current situation or your overall quality of life.

> All birds, even those of the same species, are not alike, and it is the same with animals and with human beings. The reason WakanTanka does not make two birds, or animals, or human beings exactly alike is because each is placed here by WakanTanka to be an independent individuality and to rely upon itself.
>
> —Shooter, Teton Sioux
> StoneE Producktions, 1996

Self-advocacy among Native Americans with disabilities brings its own unique challenges in many ways. Native Americans have struggled with oppression for several hundred years. It is a constant struggle to have our voices heard and to fight for our own self-determination as a people. The journey for Native Americans with disabilities is the same fight against oppression and in some cases our own family or tribal community may be the oppressor. Lack of awareness and understanding about disabilities creates an environment that feels oppressive and leaves many feeling frustrated and powerless.

The self-advocacy movement is a civil rights movement in many ways, as well. It is about improving the civil rights of people who have been and still are oppressed,

BEST COPY AVAILABLE

Self-Advocacy...What Is It?

- A civil rights movement for every person to have control over one's own life so people with disabilities are treated the same as everyone else.
- Beliefs and values
  - — Being a person first
  - — Being able to make our own decisions
  - — Believing in my value as a person
  - — Having other people believe in you as a person

—Fletcher and Keilson, 2002

ignored, devalued, and segregated because of how they are viewed as people who have or are labeled as having developmental disabilities (Shoultz, 2002).

Giving Voice to Your Life Choices

> Self-advocacy is a life-long personal pursuit of control over one's own circumstances. It is the act of advocating for what one wants, for how one desires to live, for how one wants to be treated, within one's family, community and services, and it does not end with one concession or victory.
>
> —Bonnie Shoultz, 2002

If you find talking to others difficult because it is uncomfortable or you are extremely shy, this doesn't have to keep you from communicating what you want and need in your life. If you find it hard to communicate with people or ask for what you want and need, find a friend or family member who can speak for you. Many times another person with a disability makes the best spokesperson in these situations simply because that person understands the situation from personal experience. Typically, there is someone in each tribal community who would be more than willing to assist in any way possible.

BEST COPY AVAILABLE

Speaking Up About Services

"Now, self-determination means running my own life and directing my personal care assistants on how best to assist me in my personal care. Now, people treat me like a human being who knows what I want and who needs support to live my life. They ask me what I want and how I want it done. They also ask me: what is the easiest way to get things done, so that I feel comfortable and they feel comfortable as well. So self-determination doesn't mean you have to do everything yourself, but it does mean you have to be in charge of your life to the fullest extent that you possibly can be" (Kennedy, 2002, p. 1).

> Self-advocacy means people with disabilities speaking up and speaking out for their rights. For people who can't speak, it may mean having someone interpret what you want to say.
>
> —Michael Kennedy and Patricia Killius, 2002

Tribes are very different in their awareness and attitudes about tribal members with disabilities. They are extremely diverse in their capacity and willingness to address the needs of tribal members with disabilities. It becomes increasingly important that consumers speak up about the services offered by tribes, tribal programs, and county, state, and federal agencies.

Jo White, of the Pine Ridge Quad Squad, teaches self-advocacy by telling consumers that if there are no access ramps into a building for you, and they don't provide access after you have requested them, then you plant yourself on the steps of that building and make them carry you into the building. You keep doing that, she says, and they will finally get tired of carrying you and build you a ramp.

> The system...needs to support the idea of teamwork and power sharing between people and their helpers. The system is there to assist, offering guidance but not threatening us if we don't take the advice. The system also needs to support the idea that people should be able to live how they want to, even if the professionals would live differently. This always means listening to us, really listening, and giving us feedback that is honest but respectful..
>
> —Michael Kennedy and Bonnie Shoultz, 2002

Use whatever means you have to speak up and state what you need and how you would like it done. There may be times when you

BEST COPY AVAILABLE

have to dig for services. Some tribes report that there are times when disability agencies don't tell you about all of the available resources and services; you may have to dig for the information and explore all of the avenues. You may be fortunate enough to have a tribal service provider who knows "the ropes" and can help you get the best service possible, or you may have a program staff that is new and knows nothing. Your own best advocate is yourself.

The City of San Antonio Disability Access Office has developed the following Self-Advocacy Cycle guide with information provided by the National Information Center for Handicapped Children and Youth to help you advocate for yourself. The four steps are targeting, preparing, influencing, and following through.

Step 1: Targeting

Identify individual, family, or group needs and the organizations or resources responsible for addressing these needs:

- Medical
- Therapeutic
- Family support
- Legal
- Financial
- Housing
- Recreation
- Barrier removal
- Problem diagnosis/assessment
- Education
- Independent living skills
- Social/emotional development

Step 2: Preparing

Prepare to participate in decisionmaking sessions on how best to meet your needs.

Have a friend or advocate come with you to decisionmaking meetings. Do your homework: Know the organization's personnel (names, addresses, phone numbers), so you can contact them for help and information. Know your rights and the services you are eligible to receive. Be positive; leave feelings of resentment at home.

Step 3: Influencing

Influence decisionmakers to adopt your desired approach for addressing your needs. When using the telephone or writing letters,

> You have control. Just ask for what you need.
>
> —Jo White, Pine Ridge Quad Squad

- Check with whom you are talking in order to avoid repeating your story.
- Identify yourself and specifically state the purpose of your call.
- Always be prepared to describe the essential aspects of needs that are relevant to the agency that you are calling.
- Have records available and encourage immediate action.
- Know exactly the purpose of your call and stay on that purpose until it has been achieved. If you're unsatisfied, ask to speak to someone else.
- Communicate a sense of teamwork: "How can we make this happen?"
- Know exactly what, when, and where your next steps are before hanging up.

Step 4: Following Through

Check to be certain that the agreements made are carried out.

Keep good records: It is up to you (the self-advocate) to check to see if the services that you worked hard to get are being delivered. There is no end to the process of self-advocacy. Self-advocates must reassess their needs and the services available to meet their needs on an ongoing basis. Each stage in a person's or group's development potentially means new needs, new decisionmakers to influence, and

BEST COPY AVAILABLE

new follow-up visits. Being a truly effective self-advocate is not an easy task! It demands tenacity and perseverance.

What Would You Do as a Self-Advocate?

- Know your rights
- Speak up for yourself
- Express your feelings
- Solve problems, get things done
- Make choices and make your own decisions
- Decide how support is given
- Have influence over your own life
- Help each other to express your feelings and thoughts
- Take control over your life
- Take part in things that affect your own life
- Allow yourself to make your own mistakes
- Form groups

—Fletcher and Keilson, 2002

Guidelines for Writing a Resolution

While advocating for changes affecting people with disabilities within a tribal system, it is sometimes necessary to begin with the development of tribal policy. One of the most effective ways to initiate change is through the presentation of resolutions. Each tribe and Indian organization has its own procedures set out for the creation and approval of resolutions. This section provides general guidelines on how to develop and present a resolution along with sample resolutions approved by the National Congress of American Indians.

BEST COPY AVAILABLE

Purpose of Submitting a Resolution

The purpose of writing a resolution is to provide a formal procedure whereby the members of the tribal governing body can give input concerning policy and activities. Tribal leaders and community advocates can set policy and direction through committees by way of resolutions during tribal governing procedures. A resolution is a means of expressing an opinion on a pressing matter or of recommending that some action be taken by the tribal governing body or some other agency.

Useful types of resolutions include the following:

- A request that the tribal governing body develop protections and accommodations for tribal members with disabilities
- A request that the tribal governing body establish a new program or activity or reconsider a current tribal program or activity
- A request that the tribal governing body change its operating procedures

When drafting and sponsoring a resolution, keep in mind that the wording must be carefully crafted and accurately defined. The resolution should be clear, concise, and specific. Sponsors should expect to introduce resolutions from the floor and to make impromptu defenses of the document throughout the session. Review existing tribal resolutions and follow that format.

Resolution Format

Resolutions may originate from

- Tribal government leaders
- Community advocates
- Organization members

The resolution format needs to include the resolution number, title, date, a "whereas" section that clearly defines the problem and possible resolution, certification by the tribe or organization leaders, a "refer to" designation, and the contact information for the person filing the resolution form. These components are

BEST COPY AVAILABLE

detailed in the descriptions that follow.

- Resolution Number: Supplied by the organization's secretary.
- Title: Should reflect the action for which the resolution calls.
- Date: Date submitted.
- Whereas: Many times a tribal governing body will have a template for the introductory "Whereas." The subsequent "Whereas" statements should be written clearly to define the problem and state that a solution is possible. Please remember that the "Whereas" parts are not voted on and should be limited to three or four statements in order to ensure that the focus remains on the resolved portion of the resolution.
- Resolved: Each "resolved" requests action by the tribal/organization governing body.
- Certification: This section certifies that the resolution was formally adopted by the tribal/organization governing body.
- Refer to: Each tribal/organization governing body has its own referral process. Check with tribal government/organization leaders or the designated secretary.
- Author/Contact Person: The individual who drafted the resolution and who can be contacted for clarification.

Sample Resolutions

Following are examples of existing resolutions to demonstrate how these components appear in their final form.

The National Congress of American Indians
Resolution # PSC-99-006

Title: The Establishment of a National American Indian Disability Technical Assistance Center

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and to otherwise promote the welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and composed of representatives of and advocates for national, regional, and local tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, one in three American Indians, or 759,000 tribal members, report having a disability; and

WHEREAS, tribal people and tribal people with disabilities are interested in improving services, outreach, and training but do not have access to disability-related technical expertise, equity in funding, and disability Civil Rights laws; and

WHEREAS, NCAI has provided support and acknowledgment of the need for an American Indian Disability Technical Assistance Center that is respectful of tribal

sovereignty and cultural diversity to serve American Indians and Alaska Natives through their Green Bay Resolution GRB-98-042; and

WHEREAS, the following entities have begun to meet to discuss the establishment of a National American Indian Disability Technical Assistance Center (see attached): U.S. Senate Committee on Indian Affairs; National Council on Disability (NCD); Office of Public Liaison—The White House; HHS; Department of Education's Office of Special Education Programs (OSE), Office of Special Education & Rehabilitation Services (OSERS), NIDRR, and the Rehabilitative Services Administration (RSA); DOJ, Office of Tribal Justice; DOJ, Civil Rights Division; Office of Intergovernmental Affairs; National Congress of American Indians; Department of Labor; and American Indian Rehabilitation Rights Organization of Warriors (AIRROW).

NOW THEREFORE BE IT RESOLVED, that NCAI does hereby work through the Sub-Committee on Disability Issues and strongly recommends the participation of the following entities: Indian Health Services; Bureau of Indian Affairs; HUD—Office of Native American Programs; National American Indian Housing Council (NAIHC); National Council on Independent Living (NCIL); Administration for Native Americans (ANA); and Administration on Developmental Disabilities (ADD); and

BE IT FURTHER RESOLVED, that NCAI will address Congress and the Administration to support the establishment of the AIDTAC through existing agency coordination and collaboration in seeking appropriations; and

BE IT FINALLY RESOLVED, that NCAI does hereby monitor the progress of the establishment of a National American Indian Disability Technical Assistance Center to serve the needs of all American Indian people with disabilities and their elders.

CERTIFICATION

The foregoing resolution was adopted at the 1999 Annual Session of the National Congress of American Indians, held at the Palm Springs Convention Center, in Palm Springs, California, on October 3-8, 1999, with a quorum present.

_____

Susan Masten, President

ATTEST: Juana Majel, Recording Secretary

The National Congress of American Indians
Resolution # PSC-99-005

Title: Creating an American Indian Disability Liaison Office To Better Coordinate National Disability Policy

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and to otherwise promote the welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and composed of representatives of and advocates for national, regional, and local tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and

WHEREAS, 33 percent, or one in three American Indians/Alaska Natives (759,000 total), have reported a disability or disabling condition, which equates to the highest minority population in the United Sates having disabilities; and

WHEREAS, the Indian Health Services (IHS) and the Bureau of Indian Affairs (BIA) are the designated agencies to handle the health, education, and welfare of American Indians/Alaska Natives, yet neither IHS nor BIA have the awareness, understanding, knowledge, or technical assistance to adequately address the policy and implementation of services and outreach on disability issues for people with disabilities and elders in Indian Country, and there are no coordinated efforts to do so; and

WHEREAS, the national disability community handles the national policy, service, and outreach for the United States, yet they have not awareness, understanding, knowledge, or technical assistance developed to adequately address the cultural diversity and sovereignty for the Nations, and the national disability community is to include the American Indian population in their services and outreach, yet have not adequately done so, and there are no coordinated efforts to do so.

NOW THEREFORE BE IT RESOLVED, that NCAI does hereby acknowledge the barriers created when neither IHS, BIA, or the national disability community have coordinated efforts to address national disability policy in Indian country; and

BE IT FURTHER RESOLVED, that NCAI does hereby acknowledge and recommend the need for the establishment of an American Indian Disability Liaison Office to better coordinate national policy for addressing the needs of American Indians/Alaska Natives with disabilities and their elders; and

BE IT FINALLY RESOLVED, that NCAI does hereby recommend and monitor the progress of establishing an American Indian Disability Liaison Office within the Office of Public Liaison—The White House or in the Office of Intergovernmental Affairs.

CERTIFICATION

The foregoing resolution was adopted at the 1999 Annual Session of the National Congress of American Indians, held at the Palm Springs Convention Center, in Palm Springs, California, on October 3-8, 1999, with a quorum present.

Susan Masten, President

ATTEST: Juana Majel, Recording Secretary

Adopted by the General Assembly during the 1999 Annual Session of the National Congress of American Indians, held at the Palm Springs Convention Center, in Palm Springs, California, on October 3-8, 1999.

The National Congress of American Indians
Resolution # JUN-00-018

Title: Continuation Of Disability Projects And Allocated Funding Within The Current And Next Administration For Indian Country

WHEREAS, we, the members of the National Congress of American Indians of the United States, invoking the divine blessing of the Creator upon our efforts and purposes, in order to preserve for ourselves and our descendants the inherent sovereign rights of our Indian nations, rights secured under Indian treaties and agreements with the United States, and all other rights and benefits to which we are entitled under the laws and Constitution of the United States, to enlighten the public toward a better understanding of the Indian people, to preserve Indian cultural values, and to otherwise promote the welfare of the Indian people, do hereby establish and submit the following resolution; and

WHEREAS, the National Congress of American Indians (NCAI) is the oldest and largest national organization established in 1944 and composed of representatives of and advocates for national, regional, and local tribal concerns; and

WHEREAS, the health, safety, welfare, education, economic and employment opportunity, and preservation of cultural and natural resources are primary goals and objectives of NCAI; and,

WHEREAS, projects and allocated funding have been created within the present Administration; and,

WHEREAS, the current Administration and its federal agencies are beginning to address the issues of disability in Indian country through work groups and specific disability entities under the Department of Health and Human Services; and,

WHEREAS, the incoming Administration's practice is to change priorities; and,

NOW THEREFORE BE IT RESOLVED, that NCAI recommends continued allocation for disability projects in Indian country that would enhance the tribes' ability to serve Native American people with disabilities; and,

BE IT FINALLY RESOLVED, NCAI does hereby urge federal agencies to continue to work in collaboration with each other and the tribes to address the immense disability issues facing Indian country.

CERTIFICATION

The foregoing resolution was adopted at the 2000 Mid-Year Session of the National Congress of American Indians, held at the Centennial Hall in Juneau, Alaska, on June 25-28, 2000, with a quorum present.

_____

Susan Masten, President

ATTEST:

Juana Majel, Recording Secretary

Adopted by the General Assembly during the 2000 Mid-Year Session of the National Congress of American Indians, held at the Centennial Hall in Juneau, Alaska, on June 25-28, 2000.

Resolution No. _____

SAMPLE RESOLUTION
OF THE GOVERNING BODY OF

_____

_____

A RESOLUTION TO SUPPORT THE ESTABLISHMENT OF NEEDED ACCESSIBILITY TO NATIVE AMERICANS WITH DISABILITIES

BE IT RESOLVED BY THE COUNCIL OF THE _____ THAT THERE IS A NEED TO PROVIDE ACCESSIBLITY TO NATIVE AMERICANS WITH DISABILITIES:

WHEREAS, the _____ respect the lives of all of our people and recognize that our people are the most important tribal resource; and

WHEREAS, the _____, utilizing the authority vested in them pursuant to the Tribal Constitution, has authority to protect the health, security, and general welfare of the _____; and

WHEREAS, the _____ recognize the need for tribal facilities, including recreational areas, pow-wow grounds, and other tribal areas that are operated and maintained by the _____ to be in compliance with the spirit of the American with Disabilities Act of 1990, Public Law 101-336 (104 Stat. 327) ("ADA"); and

WHEREAS, the _____recognize that no individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations of any place of tribal accommodation; and

WHEREAS, the _____further recognize that the objective of ADA is to provide mobility for Americans with disabilities and to enable them to lead normal and productive lives; and

WHEREAS, the _____are aware that an estimated 14 percent of the Native American population have disabilities and are denied social and economic enjoyment taken for granted by others who have no disabilities, e.g., employment and recreational activities, and

WHEREAS, the _____ are also aware that respondents to a recent survey of the American Indian Disability Legislation indicated that approximately 67 percent of the public buildings on the various Indian reservations are accessible, leaving almost one-fourth of the public buildings inaccessible; and

WHEREAS, the _____ have identified a need to develop a tribal policy implementing ADA in our present facilities, as well as any future (new or reconstructed) facilities; and

NOW, THEREFORE, BE IT RESOLVED, that the _____recognize that our people with disabilities are entitled to accessibility to our tribal facilities, recreational sites, pow-wow grounds, and other areas.

BE IT FURTHER RESOLVED, that the _____ are committed to developing a tribal policy to address and comply with ADA.

AND BE IT FURTHER RESOLVED, that there shall be an established committee to assist in the review process addressing the application of appropriate ADA accessibility guidelines.

AND BE IT FURTHER RESOLVED, that the _____shall direct the Tribal Division of _____ and _____, and any other tribal department whose involvement will be necessary to address and meet the guidelines of ADA and to participate in said committee to ensure compliance.

CERTIFICATION

The foregoing resolution was adopted by the Tribal Council on the ____ day of _____, ____, with a vote of ____ for, ____opposed, and ____ not voting, pursuant to authority vested in_____ by _____ as amended.

_____

Chair, Tribal Council

ATTEST:

_____

Executive Secretary

* Thanks to the Confederated Salish and Kootenai Tribes for use of their tribal resolution to improve the overall quality of life for tribal members with disabilities.

References

Fletcher, Trudy, and Keilson, Jeff, KY-SPIN, Inc. (2002). Self-advocacy. Retrieved October 7, 2002, from PNP Associates and Kentucky Council on Developmental Disability, www.kyspin.com/self_advocacy.htm.

Kennedy, Michael, The Center on Human Policy. (2002). Self-determination. Retrieved from September 27, 2002, from http://soeWeb.syr.edu/thechp/mikeself.htm.

Kennedy, Michael, and Patricia Killius, The Center on Human Policy. (2002). Self-Advocacy: Speaking for Yourself. Recorded and edited by Deborah Olson, 1986. Retrieved September 27, 2002, from http://soeWeb.syr.edu/thechp/saspeak.htm.

Kennedy, Michael, and Bonnie Shoultz, The Center on Human Policy. Thoughts about self-advocacy. Retrieved September 27, 2002, from http://soeWeb.syr.edu/thechp/thoughts.htm.

Shoultz, Bonnie, The Center on Human Policy. (2002). More thoughts on self-advocacy: the movement, the group, and the individual. Retrieved September 27, 2002, from http://soeWeb.syr.edu/thechp/moretho.htm.

StoneE Producktions. (1996). Shooter, Teton Sioux. In *Quotes From Our Native Past*. Retrieved November 4, 2002, from www.ilhawaii.net/~stony/quotes.html.

White, Jo. (September 9, 2002). Telephone interview by Martina Whelshula.

Federal Disability Laws & Tribes

BEST COPY AVAILABLE

Julie Clay

"I have a vision for the toolkit to educate and inform policymakers, tribal council members, and general society about American Indians and Alaska Natives who are living with the highest rate of disabilities. It is important to provide this information and research to people nationwide for them to really understand how a disability impacts our lives. To me that is the real important thing."

BEST COPY AVAILABLE

Federal Disability Law and Tribes

Background

Individuals with disabilities living on tribal lands face a complex legal environment. Because Indian tribes enjoy the "inherent powers of a limited sovereignty which has never been extinguished," tribal lands are subject to the jurisdiction of tribal governments, long recognized as distinct political entities. This sovereignty may also affect the application of federal regulations to tribes. Federally recognized Indian tribes, as sovereign self-governing nations, are protected from private lawsuits under the doctrine of "sovereign immunity." Tribes can be sued only if they agree to waive their sovereign immunity for that purpose.

Individuals with disabilities who are concerned about their rights and protections guaranteed under the Rehabilitation Act of 1973 (29 U.S.C. §§ 701 et seq.), or the Americans with Disabilities Act of 1992 (42 U.S.C. §§ 12101 et seq.), may face unique barriers when seeking enforcement by a tribal government.

Understanding Government-to-Government Relationships

Because of tribal sovereignty, a unique relationship exists between tribal governments and the Federal Government. This "government-to-government" relationship requires the Federal Government to recognize the tribal right to self-governance. In addition, the Federal Government must uphold its trust obligations and respect treaty rights.

To further this government-to-government relationship, the Federal Government announced a policy of consultation with tribal governments in Executive Order #13175 (November 6, 2000). The policy requires meaningful consultation with tribal officials on any regulatory policies that have tribal implications. Federal agencies are required to consult with tribes during the development of new policies. When possible, federal

agencies must grant tribes the maximum administrative discretion possible. Agencies are required to encourage tribes to formulate and implement their own policies, establish standards, and consult with tribes when developing federal standards.

The Americans with Disabilities Act (ADA) and Tribes

Title I: Title I of ADA requires that employers with 15 or more employees provide qualified individuals with a disability with an equal opportunity to benefit from the full range of employment benefits available to others. Title I of ADA restricts discrimination in hiring, promotions, pay, and other privileges of employment. Employers must make reasonable accommodation for the known physical or mental limitations of otherwise qualified individuals with disabilities, unless it results in an undue hardship. However, Title I categorically excludes tribes as employers.

Title II: On June 22, 1999, the Supreme Court decided a landmark ruling interpreting Title II of the Americans with Disabilities Act. This decision, in *Olmstead v. L.C.* (527 U.S. 581 (1999)), found that Title II of ADA requires states to provide community-based treatment for persons with mental disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated. When considering whether the placement can be reasonably accommodated, it is necessary to consider the resources available to the state and the needs of others with mental disabilities. The practical application of this ruling is that states must help to provide the least restrictive level of care for people with disabilities, moving away from institutionalization and toward home- and community-based care. This could present new opportunities for tribal governments to develop home- and community-based services that are reimbursed by Medicaid or other sources.

Title III: In passing Title III of ADA, Congress announced the purpose as providing "a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." Title III of ADA attempts to accomplish this goal by prohibiting discrimination in public accommodations. Based on Congress' intent to end discrimination and the statute's broad language, federal courts have ruled that Title III of ADA applies to tribes.

However, a federal court finding that a statute is applicable to a tribe is not the same as finding a waiver of tribal sovereign immunity. While Title III of ADA may apply to tribes, sovereign immunity prohibits private suits for enforcement against tribes in federal courts. In such cases, individuals with disabilities may have a right without a remedy.

Although Title III of ADA does provide for suits brought for enforcement by DOJ, no such action has been brought.

The Rehabilitation Act and Tribes

The Rehabilitation Act prohibits discrimination based on disability in programs conducted by federal agencies, including programs receiving federal funds and in federal employment. In determining employment discrimination, the Rehabilitation Act uses the same standards as Title I of ADA.

Section 121 of the Rehabilitation Act authorizes the Rehabilitation Services Administration to make grants to tribes for the purpose of VR services. Tribes accepting these grants, and generally other federal funds, agree to comply with federal law. However, this agreement does not amount to a waiver of sovereign immunity, which protects tribes from suit in federal court. Again, individuals with disabilities may have a right without a remedy.

The Individuals with Disabilities Education Act (IDEA) and Tribes

The purpose of IDEA is to ensure that every child has available to him/her a free, appropriate public education that meets individual needs. IDEA intends to improve the educational results of children with disabilities. To reach this goal, IDEA requires first that a child suspected to have a disability be evaluated by the school. Second, IDEA requires an Individualized Education Program (IEP) be developed by a specific team of people including, among others, the parents and teachers, for each eligible child with a disability. The IEP must be based upon individual needs.

IDEA provides that the Secretary of the Interior receive funds from the Secretary of Education to educate children with disabilities aged 5 to 21 on reservations in elementary and secondary schools operated and funded by the Bureau of Indian

Affairs (BIA). IDEA also provides an administrative enforcement process that BIA-funded schools are subject to, based upon the school's status as a local educational agency for funding purposes. Tribally operated schools that accept IDEA funds from BIA must also abide by the provisions of the law.

If IDEA requirements are not met, IDEA provides for dispute resolution mechanisms. For BIA-funded schools, BIA acts as a state with responsibility for ensuring that IDEA requirements are met and for operating mechanisms for resolving disputes. These mechanisms include (1) mediation; (2) formal complaint process; and (3) due process or litigation.

Advocacy

The outcomes above may suggest that tribal governments are failing to meet their responsibility to individuals with disabilities; the reality is that current funds may not be significant enough to improve accessibility on tribal lands. Although entangled in this complex legal environment, individuals with disabilities living on tribal lands have potential options. A tribe could waive its sovereign immunity to allow suits brought under ADA, tribal courts could enforce federal disability legislation, or tribal governments could pass ordinances providing protections similar to those in federal statutes, such as ADA or Rehabilitation Act.

The political power of people with disabilities, their families, and advocates could help to move tribal governments toward adopting such ordinances. However, model legislation may be inappropriate because tribes vastly differ from one another. The legislation addressing disabilities may be more effective if specifically developed for particular tribes. Tribes that have worked on such ordinances include the Salish Kootenai, the Navajo, and the St. Regis Mohawk.

Improvements in accessibility will incur costs. The Federal Government, in fulfilling its trust obligations, can and should provide funding to meet these requirements. A tribe's immunity from suit in federal court should not result in a tribe's conclusion that ADA is inapplicable. In drafting ADA, Congress makes it clear that the Act is a "national mandate" to end discrimination. Furthermore, the Act, other comparable legislation, and the legislative histories suggest that Indian tribes should be the recipient of grants to ensure compliance.

References

Florida Paraplegic Association, Inc. v. Miccosukee Tribe of Indians of Florida, 166 F.3d 1126 (11th Cir. 1999).

Sanderlin v. Seminole Tribe, 243 F.3d 1282 (11th Cir. 2001).

United States v. Wheeler, 435 U.S. 313, 322 (1978).

Worcester v. Georgia, 31 U.S. 515, 559 (1832).

National Initiatives, Federal Agencies, & National Organizations

BEST COPY AVAILABLE

National Initiatives, Federal Agencies, and National Organizations

Background

Federal agencies and national organizations play important roles in increasing accessibility for individuals with disabilities. Both were integral in passing the Americans with Disabilities Act (ADA) in 1990, and both continue working today to improve the opportunities for individuals with disabilities in education, transportation, and participation in their communities.

Initiatives

Even with all the success in the 12 years since the passage of ADA, the Federal Government is still working to improve access for individuals with disabilities. The descriptions of the initiative that follows demonstrate the current administration's position on improving services for individuals with disabilities.

New Freedom Initiative

Announced by President Bush on February 1, 2001, the New Freedom Initiative is an effort to remove barriers preventing people with disabilities from accessing new technologies, education, and full integration into American life. The Initiative announces an administration effort to increase funding for the Individuals with Education Act, integrating Americans with disabilities into the workforce and promoting full access to community life. (Visit www.whitehouse.gov/news/freedominitiative/freedominitiative.html to view the legislation.)

To further the goals of the New Freedom Initiative, President Bush announced Executive Order 13217. This Order, issued June 18, 2001, directs the Federal Government to assist state governments in implementing the Supreme Court's decision in *Olmstead v. L.C.* The Order commits the attorney general, secretaries of Health and Human Services, Education, Labor, and Housing and Urban Development, as well as the Commissioner of Social Security, to improve the availability of community-based services for people with disabilities.

Federal Disability Agencies

Congress has enacted disability legislation with the role of program administration and enforcement existing within many diverse federal agencies. The needs of individuals with disabilities cut across all aspects of life; the number and type of agencies providing services for individuals with disabilities reflect this wide spectrum. The "Guide to Disability Rights Laws," published by the Department of Justice (DOJ), provides an excellent introduction to the services and agencies that are outlined in the following pages (DOJ, 2001).

Social Security

The Social Security Administration has two types of programs that can benefit people with disabilities:

- **Social Security Disability Insurance:** This program pays benefits to you and/or certain members of your family, if you become disabled *and* you are insured, meaning that you worked long enough and paid into the Social Security tax system. To qualify for benefits you must first have worked in jobs covered by Social Security. Then you must have a medical condition that meets Social Security's definition of disability. Generally, this program will pay cash benefits to a person who has not been able to work for a year or more because of a disability.
- **Supplemental Security Income (SSI):** This program will pay benefits based upon financial need to people with disabilities. SSI was established to assist people who are aged, blind, or have a disability and have little or no financial income. It provides cash payments to meet basic needs such as food, clothing, and shelter. If you get SSI, you will usually also get Food Stamps and Medicaid assistance.

How does Social Security define a "disability"? The Social Security Administration uses the same basic definition for both Social Security Disability Insurance and SSI programs. A disability means that you have a physical or mental problem that keeps you from working and is expected to last at least a year or to result in death.

How do I apply for SSI? To apply for SSI you can contact your local Social Security office or contact the main office at 1-800-772-1213 to make an appointment with a Social Security representative. If you have an advocate or family member who will make these appointments for you, be sure to give that person written permission to speak on your behalf.

Other things to bring to your SSI appointment:

- Your Social Security card or a record of your Social Security number
- Your birth certificate or other proof of your age
- Information about the home you live in, such as your mortgage or lease and landlord's name
- Payroll slips, bank books, insurance policies, burial fund records, and other information about your income and the things that you own (remember that American Indians and Alaska Natives can exempt up to $2,000 in assets from trust income related to their status as tribal members)
- If you're signing up for disability—the names, addresses, and telephone numbers of doctors, hospitals, and clinics that have seen you
- Proof of U.S. citizenship
- Checkbook or other banking or credit union information with your account number so that you can have your benefits automatically deposited into your account once approved

How do I apply for Social Security Disability Insurance benefits? It will take longer to apply for Social Security Disability Insurance benefits than for other programs under Social Security, usually 60 to 90 days. You should make an appointment with your local Social Security office to get your application moving. This office will send your application to the Disability Determination Services office located in your state to determine whether you meet the definition of a person with a disability under the law.

You should bring the following information with you to your appointment:

- Social Security number and proof of age for each person applying for payments
- Names, addresses, and phone numbers of doctors, hospitals, clinics, and institutions that treated you, and dates of treatment
- Names of all medications you are taking
- Medical records from your doctors, therapists, hospitals, clinics, and caseworkers
- Laboratory test and test results
- A summary of where you have worked and the kind of work you did
- A copy of your W-2 form (Wage and Tax Statement) or, if self-employed, your federal tax return for the past year
- Dates of prior marriages if your spouse is applying

(NOTE: If you don't have all the information, start your application process and work with the Social Security office to get the additional information.)

Never take "no" for an answer. Even if you are declined for benefits under SSI or Social Security Disability, you should appeal that decision and work with an advocate or your Social Security office to get whatever additional information you need to qualify.

For more information about the appeals process, you may call the toll-free number, 1-800-772-1213, and ask for the SSI fact sheet called "The Appeals Process," publication number 05-10041, and "Social Security And Your Right to Representation," publication number 05-10075. You can also access publications on the Internet at www.ssa.gov/pubs/englist.html. All requests for appeals should be sent to your local office; you can find the address of your local office at www.ssa.gov/locator.

National Council on Disability (NCD)

NCD is an independent federal agency consisting of 15 members appointed by the President and confirmed by the U.S. Senate. The goal of NCD is to promote policies that ensure equal opportunity for all individuals with disabilities. By making

recommendations to the President and Congress, NCD works to ensure that all individuals with disabilities have an opportunity to work, live independently, and integrate into all aspects of society.

Department of Justice

Title III of the Americans with Disabilities Act authorizes the U.S. Attorney's office to sue entities discriminating against individuals with disabilities. DOJ is also responsible for enforcing Section 504 of the Rehabilitation Act, which prohibits any program or activity receiving federal funds from discriminating against any qualified individual with a disability.

Equal Employment Opportunity Commission (EEOC)

Title I of ADA prohibits disability-based discrimination by employers. ADA directs complaints under Title I to be filed with the EEOC. Complaints must be filed with the EEOC within 180 days of the discriminatory act.

Rehabilitation Services Administration (RSA)

The Rehabilitation Act authorizes grants to tribes to carry out VR programs. The Rehabilitation Act authorizes RSA under Section 121 to make grants to tribal governments for the costs of vocation rehabilitation of Indians with disabilities.

Department of the Interior

The Bureau of Indian Affairs is located within the Department of the Interior. BIA, which administers tribal schools, is responsible for the education of individuals with disabilities within these schools. BIA's larger mission is to enhance the quality of life, to promote economic opportunity, and to protect and improve the trust assets of American Indians, Indian tribes, and Alaska Natives. BIA seeks to accomplish this by delivering quality services and maintaining government-to-government relationships within the spirit of Indian self-determination. (Currently, access to the Department of the Interior Web site is restricted in compliance with a court order.)

Administration on Developmental Disabilities (ADD)

The ADD ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports, and other assistance and opportunities that promote independence, productivity, and integration and inclusion into the community.

Department of Labor

In the fiscal year 2001 Department of Labor appropriation, Congress approved an Office of Disability Employment Policy (ODEP) to be headed by an assistant secretary. ODEP's mission is to provide leadership to increase employment opportunities for adults and youth with disabilities. ODEP is a federal agency in the Department of Labor.

Administration on Aging (AOA)

AOA provides home- and community-based services to millions of vulnerable and hard-to-reach older persons through programs funded under the Older Americans Act. Among these services are nutrition, such as home-delivered meals or meals served in congregate settings; transportation; legal assistance; and health promotion counseling and training. AOA's National Family Caregiver Support Program focuses on those caring for family members who are chronically ill or who have disabilities. The program also helps those who are caring for younger family members, such as grandchildren and those with mental retardation or developmental disabilities.

Centers for Medicare and Medicaid Services (CMS)

CMS is a federal agency within the U.S. Department of Health and Human Services. CMS runs the Medicare and Medicaid programs—two national health care programs that benefit about 75 million Americans. And with the Health Resources and Services Administration, CMS runs the State Children's Health Insurance Program, a program that is expected to cover many of the approximately 10 million uninsured children in the United States.

Department of Housing and Urban Development (HUD)

HUD offers programs, assistance, and loan programs specifically for Native American tribes, organizations, and sometimes individuals. HUD offers information on basic homebuying, fair housing, and housing counseling.

Office of Special Education Rehabilitation Services (OSERS)

OSERS provides leadership to achieve full integration and participation in society of people with disabilities by ensuring equal opportunity and access to, and excellence in, education, employment, and community living. OSERS supports programs that help educate children and youth with disabilities and supports research to improve the lives of individuals with disabilities.

Regional Rehabilitation Continuing Education Programs (RRCEPs)

RRCEPs are training centers that serve a federal region by providing a broad integrated sequence of training activities that focus on meeting recurrent and common training needs of employed rehabilitation personnel. General RRCEPs provide training for state VR agency staff. Community Rehabilitation Program (CRP) RRCEPs provide training programs for staff of related public and private nonprofit rehabilitation agencies. Generally, RSA funds one general and one CRP RRCEP per Department of Education Region (Region IV has two general RRCEPs).

Rural Utilities Service

Rural Utilities Service is a Rural Development Agency of the U.S. Department of Agriculture. It helps rural America finance electric, telecommunications, and water and wastewater projects and make loans and grants for rural distance learning and telemedicine projects. It is also a policy and planning rural advocacy agency.

Small Business Administration (SBA)

SBA, created by Congress in 1953, helps America's entrepreneurs form successful small enterprises. SBA's program offices, in every state, offer financing, training, and advocacy for small firms. SBA works with thousands of lending, educational, and training institutions nationwide. If your business is independently owned and operated, not dominant within its field, and within certain size standards, the SBA can help.

Temporary Assistance for Needy Families (TANF)

All states, territories, the District of Columbia, and all federally recognized tribes in the lower 48 states and 13 specified entities in Alaska are eligible. TANF programs must operate under plans approved by HHS. Needy families with children are

determined to be eligible by the state, territory, or tribe in accordance with the state or tribal plan submitted to HHS. Needy families must meet state or tribal eligibility requirements.

Administration for Native Americans (ANA)

ANA promotes the goal of social and economic self-sufficiency of American Indians, Alaska Natives, Native Hawaiians, and other Native American Pacific Islanders, including Native Samoans. Self-sufficiency is that level of development at which a Native American community can control and internally generate resources to provide for the needs of its members and meet its own economic and social goals. Social and economic underdevelopment is the paramount obstacle to the self-sufficiency of Native American communities and families.

ANA is the only federal agency serving all Native Americans, including over 500 federally recognized tribes, 60 tribes that are state recognized or seeking federal recognition, Indian organizations, over 200 Alaska villages, Native Hawaiian communities, and populations throughout the Pacific Basin.

National Disability Organizations

A number of private organizations are dedicated to improving services for individuals with disabilities, including organizations concerned specifically with the needs of American Indians and Alaska Natives.

American Indian Disability Technical Assistance Center (AIDTAC)
The University of Montana Rural Institute
Center of Excellence in Disability Education, Research, and Services
52 Corbin Hall
Missoula, MT 59812-7056
Phone: (800) 732-0323; (406) 243-5467

AIDTAC, funded by a grant from the RSA, is an informational and technical assistance resource available to tribes. AIDTAC's goal is to assist tribes in formulating and implementing programs and policies that will reduce barriers to independent living and to provide opportunities for employment to individuals with disabilities.

American Indian Rehabilitation Research and Training Center (AIRRTC)
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86001-5630
Phone: (928) 523-4791
Fax: (928) 523-9127
TTY/TDD: (928) 523-1695
Web site: www4.nau.edu/ihd/airrtc/located.htm

The mission of AIRRTC is to improve the quality of life for American Indians and Alaska Natives with disabilities through the conduct of research and training that will result in culturally appropriate and responsive rehabilitation services, to improve employment outcomes and facilitate access to services for American Indians and Alaska Natives with disabilities, and to increase the participation of American Indians and Alaska Natives in the design and delivery of rehabilitation services for employment outcomes.

Consortia of Administrators for Native American Rehabilitation (CANAR)
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86001-5630
Phone: (928) 523-4791
Fax: (928) 523-9127
TTY/TDD: (928) 523-1695
Web site: www4.nau.edu/ihd/airrtc/located.htm

**Through September 30, 2003, CANAR will use the AIRRTC office as its administrative headquarters.*

The mission of CANAR is to serve as an avenue for collaboration and cooperation between administrators of rehabilitation projects serving Native American persons with disabilities and to increase and enhance the quality of services, resulting in positive outcomes for Native American persons with disabilities.

Intertribal Deaf Council (IDC)
PO Box 17664
Salem, OR 97305
TTY/TDD: (301) 577-5665
Fax: (503) 304-1961
E-mail: intertribaldeaf@aol.com
Web site: www.deafnative.com

The IDC is a nonprofit organization of deaf and hard-of-hearing American Indians whose goals are similar to many Native American organizations. The IDC promotes the interests of its members by fostering and enhancing their cultural, historical, and linguistic tribal traditions. The council not only discusses issues related to the social, educational, economic, and environmental well-being of its members but also strives to provide useful information on human rights and resources for solutions.

National Youth Leadership Network (NYLN)
Web site: www.nyln.org/index.php

The National Youth Leadership Network (NYLN) is dedicated to advancing the next generation of disability leaders. It accomplishes this task by doing the following:

- Promoting leadership development, education, employment, independent living, and health and wellness among young leaders representing the diversity of race, ethnicity, and disability in the United States
- Fostering the inclusion of young leaders with disabilities into all aspects of society at national, state, and local levels
- Communicating about issues important to youth with disabilities and the policies and practices that affect their lives

American Association of People with Disabilities
1819 H Street NW, Suite 330
Washington, DC 20006
Phone: (800) 840-8844; (202) 457-0046
Fax: (202) 457-0473
Web site: www.aapd.com

The American Association of People with Disabilities is a nonprofit, nonpartisan, cross-disability membership organization whose goals are unity, leadership, and impact. Membership is $19.95 per year.

American Indian Rehabilitation Rights Organization of Warriors (AIRROW)
Phone: (406) 883-3817

AIRROW is a grassroots, unincorporated organization whose goal is to improve the lives of American Indians with disabilities.

American Indian Higher Education Consortium (AIHEC)
121 Oronoco Street
Alexandria, VA 22314
Phone: (703) 838-0400
Fax: (703) 838-0388 fax
E-mail: aihec@aihec.org

AIHEC's mission is to support the work of tribal colleges and the national movement for tribal self-determination. AIHEC identifies four objectives: maintain commonly held standards of quality in American Indian education; support the development of new tribally controlled colleges; promote and assist in the development of legislation to support American Indian higher education; and encourage greater participation by American Indians in the development of higher education policy.

Association of Programs in Rural Independent Living (APRIL)
Linda Gonzales
5903 Powder Mill Road
Kent, OH 44240
Phone: (330) 678-7648
Fax: (330) 678-7658
Web site: http://april.umt.edu

APRIL is a national network of rural independent living centers, other programs, and individuals concerned with the unique aspects of rural independent living. APRIL is a nonprofit, 501(c)(3) organization that promotes independence and strives for full rights and benefits of persons with disabilities living in rural America.

Council of State Administrators of Vocational Rehabilitation (CSAVR)
Suite 330
4733 Bethesda Avenue
Bethesda, MD 20814
Phone: (301) 654-8414
Fax: (301) 654-5542
Web site: www.rehabnetwork.org

Institute for Community Inclusion/UCE
UMass Boston
100 Morrissey Boulevard
Boston, MA 02125
Phone: (617) 287-4300
Fax: (617) 287-4352
Web site: www.communityinclusion.org

The Institute supports employing people with disabilities in community settings; supporting children and young adults with special health care needs; accessing general education and transitioning from school to adult life; expanding local recreation and school activities to include people with disabilities; promoting technology that aids participation in school/community/work activities; building organizations' abilities to serve culturally diverse people with disabilities; and examining the impact of national and state policies on people with disabilities and their families.

Job Accommodation Network (JAN)
West Virginia University
PO Box 6080
Morgantown, WV 26506-6080
Phone: (800) 526-7234; (800) ADA-WORK; (304) 293-7186
Fax: (304) 293-5407
Web site: http://janWeb.icdi.wvu.edu

JAN is a free consulting service that provides information about job accommodations, ADA, and the employability of people with disabilities.

Minority Business Development Agency (MBDA)
U.S. Department of Commerce
Minority Business
Washington, DC 20230
Phone: (202) 482-0404
Fax: (202) 482-2678
E-mail: help@mbda.gov
Web site: www.mbda.gov

MBDA provides management and technical assistance; information, and advice on starting, managing, and expanding a business enterprise to socially or economically disadvantaged individuals. MBDA also assists public- and private-sector organizations to increase purchases from minority vendors. MBDA does not provide any grants, loans, or loan guarantees to purchase, start, or run a business. MBDA will, however, fund organizations to provide management and technical assistance to minority entrepreneurs. MBDA administers the Minority Business Development Center Program, which helps existing minority-owned firms expand and avoid failure. Centers assist with business financial planning, management, and marketing, bid estimating and construction bonding, loan packing, and other business services.

National American Indian Housing Council (NAIHC)
900 2nd Street NE, Suite 305
Washington, DC 20002
Phone: (202) 789-1754; (800) 284-9165
Fax: (202) 789-1758
Web site: http://naihc.indian.com/index.html

National Congress of American Indians (NCAI)
1301 Connecticut Avenue NW, Suite 200
Washington, DC 20036
Phone: (202) 466-7767
Fax: (202) 466-7797
Web site: www.ncai.org

NCAI's mission is to inform the public and the Federal Government on tribal self-government, treaty rights, and a broad range of federal policy issues affecting tribal governments. NCAI includes a subcommittee on disabilities.

National Council on Independent Living (NCIL)
1916 Wilson Boulevard, Suite 209
Arlington, VA 22201
Phone: (703) 525-3406
TTY/TDD: (703) 525-4153
Fax: (703) 525-3409
E-mail: ncil@ncil.org
Web site: www.ncil.org

NCIL is a membership organization that advances the independent living philosophy and advocates for the human rights of, and services for, people with disabilities to further their full integration and participation in society.

National Indian Council on Aging (NICOA)
10501 Montgomery Boulevard NE, Suite 210
Albuquerque, NM 87111-3846
Phone: (505) 292-2001
Fax: (505) 292-1922
Web site: www.nicoa.org/index1.html

NICOA serves as the foremost nonprofit advocate for the nation's (estimated) 296,000 American Indian and Alaska Native elders. NICOA strives to better the lives of the nation's indigenous seniors through advocacy, employment training, dissemination of information, and data support.

National Indian Education Association (NIEA)
700 North Fairfax Street, Suite 210
Alexandria, VA 22314
Phone: (703) 838-2870
Fax: (703) 838-1620
E-mail: niea@niea.org
Web site: www.niea.org

NIEA's mission is to support traditional Native cultures and values, to enable Native learners to become contributing members of their communities, to promote Native control of educational institutions, and to improve educational opportunities and resources for American Indians, Alaska Natives, and Native Hawaiians throughout the United States.

National Indian Health Board (NIHB)
101 Constitution Avenue NW, Suite 8B09
Washington, DC 20001
Phone: (202) 742-4262
Fax: (202) 742-4285
E-mail: jgrimm@nihb.org
Web site: www.nihb.org

NIHB represents tribal governments operating their own health care delivery systems through contracting and compacting, as well as those receiving health care directly from the IHS. NIHB is a nonprofit organization that conducts research, policy analysis, program assessment and development, national and regional meeting planning, training and technical assistance programs, and project management. Services are provided to tribes, area health boards, tribal organizations, federal agencies, and private foundations.

United Parent Syndicate on Disabilities (UPSD)
The Drew Building
5727 Palazzo Way, Suite B
Douglasville, GA 30134
Phone: (770) 577-3307; (202) 223-4295 (Washington, DC, office)
E-mail: united_parent@mindspring.com
Web site: www.peppac.org

UPSD is a nonprofit organization dedicated to empowering parents. UPSD provides its members with the most up-to-date information on the activities of all three branches of government that affect individuals with disabilities and their families.

Office of Indian Education Programs (OIEP)
1849 C Street NW
MS-3512 MIB
Washington, DC 20240
Phone: (202) 208-6123
Fax: (202) 208-3312
Web site: www.oiep.bia.edu

The mission of BIA's OIEP is to provide quality education opportunities from early childhood through life in accordance with each tribe's needs for cultural and economic well-being in keeping with the wide diversity of Indian tribes and Alaska Native villages as distinct cultural and governmental entities.

Oyaté Project—"Metakuý Oyasin" or "All My Relations"
Center for Continuing Education in Rehabilitation
6912 220th Street SW #105
Mountlake Terrace, WA 98043
Phone: (425) 774-4446; (888) 377-0100
Fax: (425) 774-9303
Web site: www.ccer.org/natamer/oyate.htm

The Oyaté Project, administered through Western Washington University's Capacity Building Project, offers assistance to Native American Vocational Rehabilitation Projects (Section 121) in recruiting, retaining, and developing staff in order to enhance their capacity to serve their consumers.

Montana Rural Institute on Disabilities (RID)
The University of Montana
52 Corbin Hall
Missoula, MT 59812
Phone: (800) 732-0323; (406) 243-5467
Fax: (406) 243-4730
Web site: http://ruralinstitute.umt.edu

RID, a part of the national network of programs funded by the ADD, is committed to assisting in the provision of interdisciplinary training, research, service demonstration programs, leverage of funds, and information dissemination to support the independence, productivity, and inclusion into the community of people with developmental disabilities.

RTC: Rural—Research and Training Center on Rural Rehabilitation Services
The University of Montana
52 Corbin Hall
Missoula, MT 59812
Phone: (888) 268-2743; (406) 243-2460
Fax: (406) 243-4730
Web site: http://rtc.ruralinstitute.umt.edu

RTC: Rural is funded by the U.S. Department of Education. Rural Americans with disabilities and those who serve them experience problems with access to transportation and housing, employment and self-employment, independent living services, health and wellness facilities, and inclusion in community planning and activities. Our goal is to use scientific methods to develop solutions to these wide-ranging problems.

San Diego State University (SDSU)
Interwork Institute
3590 Camino Del Rio North
San Diego, CA 92108
Phone: (619) 594-4220
Fax: (619) 594-4208

In 1994, SDSU's Interwork Institute was awarded a cooperative agreement to establish the Rehabilitation Research and Training Center of the Pacific to address critical issues related to the needs of Pacific Islanders with disabilities. Research and training is conducted in the State of Hawaii, the Republic of Palau, the Federated States of Micronesia (Chuuk, Kosrae, Pohnpei, Yap), the Republic of the Marshall Islands, the Territory of Guam, the Commonwealth of the Northern Marianas, and the Territory of American Samoa. SDSU is an AIDTAC partner.

United Southern and Eastern Tribes, Inc. (USET)
711 Stewarts Ferry Pike, Suite 100
Nashville, TN 37214
Phone: (615) 872-7900
Fax: (615) 872-7417
Web site: http://usetinc.org

USET, Inc., composed of 25 nations, is dedicated to enhancing the development of Indian tribes, improving the capabilities of tribal governments, and assisting the member tribes and their governments in dealing effectively with public policy issues and in serving the broad needs of Indian people.

World Institute on Disability (WID)
510 16th Street, Suite 100
Oakland, CA 94612
Phone: (510) 763-4100
TTY/TDD: (510) 208-9496
Fax: (510) 763-4109
E-mail: Webpoobah@wid.org
Web site: www.wid.org

WID is a nonprofit, public policy center dedicated to promoting independence and full societal inclusion of people with disabilities.

Work Incentives Transition Network (WITN)
Virginia Commonwealth University
Rehabilitation Research and Training Center
1314 West Main Street
Richmond, VA 23284
Phone: (804) 828-1851
E-mail: tcblanke@saturn.vcu.edu
Web site: www.vcu.edu/rrtcWeb/witn/ssi.htm

WITN is a collaborative project funded by the U.S. Department of Education, Office of Special Education Programs. The Network's purpose is to increase educators', family members', transition age students', and advocates' awareness of Social Security Work Incentives for school-aged youth with disabilities including the Plan for Achieving Self-Support, the Impairment Related Work Expense, and the Student Earned Income Exclusion.

National Association of Protection and Advocacy Systems (NAPAS)
900 2nd Street NE, Suite 211
Washington, DC 20002
Phone: (202) 408-9514
Fax: (202) 408-9520
E-mail: info@napas.org
Web site: www.protectionandadvocacy.com

NAPAS works in partnership with people with disabilities to protect, advocate for, and advance their human, legal, and service rights. NAPAS strives toward a society that values all people and supports their rights to dignity, freedom, choice, and quality of life.

Native American Association of Protection and Advocacy
DNA—People's Legal Services, Inc.
PO Box 392
Shiprock, NM 87240
Phone: (505) 368-3216
Fax: (505) 368-3220
E-mail: Tyanan@dnalegalservices.org

Consumers who contact these organizations can also learn of any available assistance located closer to their homes. Legal staff can suggest additional resources to help children and parents.

References

Castle, Michael Rep. (2002). Opening Statement of Hearing on "Rethinking Special Education: How to Reform the Individuals with Disabilities Education Act." Committee on Education and the Workforce, Subcommittee on Education Reform. Retrieved May 2, 2002, from http://edworkforce.house.gov/hearings/107th/edr/idea/5202/oscastle.htm.

United States Department of Justice (DOJ), Civil Rights Division. (2001, August). Guide to disability rights laws. Retrieved August 2002, from www.usdoj.gov/crt/ada/cguide.htm.

Disability Etiquette Handbook

BEST COPY AVAILABLE

Disability Etiquette Handbook

People with disabilities are people first. They are not their conditions or diseases. Lack of awareness about disabilities can lead to unintended stereotypes and discrimination. How we view and communicate with and about people with disabilities shape our relationships. This guiding principle is as true in American Indian and Alaska Native communities as it is in the general population. American Indian and Alaska Native people with disabilities want to be dealt with as people.

How we refer to people with disabilities in our communication is important. For example, a person is not an *epileptic* but rather a *person who has epilepsy*. In any reference, article, announcement, or advertisement, "people with disabilities" is the appropriate and preferred initial reference. Subsequent references can use the terms "person with a disability" or "individuals with disabilities" for grammatical or narrative reasons. Please refer to the Glossary of Acceptable Terms below for a complete listing of acceptable terms and appropriate applications.

This section contains information and awareness-building resources to assist in developing effective and respectful communication practices within our Native communities. This resource can be particularly useful to new program staff who have not worked in the area of disabilities before and to help orient tribal leaders and other community program staff who want to better understand how to work effectively for people with disabilities in tribal communities. The AI/AN consumers who served on the Technical Expert Panel that designed this Toolkit believed very strongly that a brief guide was needed to help tribal programs and tribal leaders understand fundamental dos and don'ts regarding people with disabilities.

Dos and Don'ts

- Do learn where to find and recruit people with disabilities.
- Do learn how to communicate with people who have disabilities.
- Do ensure that your applications and other company forms do not ask disability-related questions and that they are in formats that are accessible to all persons with disabilities.
- Do have written job descriptions that identify the essential functions of each job.
- Do ensure that requirements for medical examinations comply with the Americans with Disabilities Act (ADA).
- Do relax and make the applicant feel comfortable.
- Do provide reasonable accommodations that the qualified applicant will need to compete for the job.
- Do treat an individual with a disability the same way you would treat any applicant or employee—with dignity and respect.
- Do know that among those protected by ADA are qualified individuals who have AIDS or cancer or who are mentally retarded, traumatically brain-injured, deaf, blind, or learning disabled.
- Do understand that access includes not only providing environmental access, but also making forms accessible to people with visual or cognitive disabilities and making alarms and signals accessible to people with hearing disabilities.
- Do develop procedures for maintaining and protecting confidential medical records.
- Do train supervisors on making reasonable accommodations.
- Don't assume that persons with disabilities do not want to work.
- Don't assume that alcoholism and drug abuse are not real disabilities, or that recovering drug abusers are not covered by ADA.
- Don't ask if a person has a disability during an employment interview.
- Don't assume that certain jobs are more suited to persons with disabilities.
- Don't hire a person with a disability if that person is at significant risk of substantial harm to the health and safety of the public and there is no reasonable accommodation to reduce the risk or harm. Do not make this decision yourself. Consult with an attorney or personnel director when making

such a determination. Your assumptions about a disability may be incorrect or unfounded.

- Don't hire a person with a disability who is not qualified to perform the essential functions of the job even with a reasonable accommodation.
- Don't assume that you have to retain an unqualified employee with a disability.
- Don't assume that your current management will need special training to learn how to work with people with disabilities.
- Don't assume that the cost of accident insurance will increase as a result of hiring a person with a disability.
- Don't assume that the work environment will be unsafe if an employee has a disability.
- Don't assume that reasonable accommodations are expensive.
- Don't speculate or try to imagine how you would perform a specific job if you had the applicant's disability.
- Don't assume that you don't have any jobs that a person with a disability can do.
- Don't assume that your work place is accessible.
- Don't make medical judgments.
- Don't assume that a person with a disability can't do a job because of apparent or nonapparent disabilities.

Conversation Etiquette

When talking to a person with a disability, look at and speak directly to that person, rather than the companion. When an interpreter is present, please look at the person who is deaf, not the interpreter, when communicating.

Relax. Don't be embarrassed if you happen to use accepted common expressions such as "See you later" or "Got to be running along" that seem to relate to the person's disability.

To get the attention of a person who is deaf or hard of hearing, tap the person on the shoulder, wave your hand, or, in a large group, flicker the lights. Look directly at the person and speak clearly, naturally, and slowly to establish whether the person can

read lips. Not all persons who are deaf can lip-read. Those who can will rely on facial expression and other body language to help in understanding. Show consideration by placing yourself under or near a light source and keeping your hands and food away from your mouth when speaking. Keep mustaches well-trimmed. Shouting won't help. Written notes to the person who is deaf or hard of hearing, however, may help facilitate the communication process.

When talking with a person in a wheelchair for more than a few minutes, sit in a chair, whenever possible, in order to place yourself at the person's eye level to facilitate conversation. When greeting a person with a severe loss of vision, always identify yourself and others who may be with you.

Example: *On my right is Candice Red Shawl.*

When conversing in a group, give a vocal cue by announcing the name of the person to whom you are speaking. Speak in a normal tone of voice, indicate in advance when you will be moving from one place to another, and let it be known when the conversation is at an end.

Listen attentively when you're talking to a person who has a speech disability. Keep your manner encouraging rather than correcting. Exercise patience rather than attempting to speak for a person with a speech difficulty. When necessary, ask short questions that require short answers or a nod or a shake of the head. Never pretend to understand if you are having difficulty doing so. Repeat what you understand, or incorporate the interviewee's statements into each of the following questions. The person's reactions will clue you in and guide you.

If you have difficulty communicating, be willing to repeat or rephrase a question. Open-ended questions are more appropriate than closed-ended questions. Examples:

Closed-Ended Question: *You were a case manager in Social Services with the Three Affiliated Tribes for seven years. Is that correct?*

Open-Ended Question: *Tell me about your recent position as a case manager.*

Do not shout at a person with a disability. Shouting distorts speech for a deaf or hard-of-hearing person and is inappropriate for a blind or low vision person who can hear.

Glossary of Acceptable Terms

Person with a disability. (Unacceptable: Handicapped or impaired)

Disability, a general term used for functional limitation that interferes with a person's ability to walk, hear, or lift, for example. It may refer to a physical, mental, or sensory condition. (Unacceptable: Impaired, handicap, handicapped person, or handicapped)

People with cerebral palsy, people with spinal cord injuries. (Unacceptable: Cerebral palsied, spinal cord injured. Never identify people solely by their disability.)

Person who had a spinal cord injury, polio, a stroke, etc., or **a person who has multiple sclerosis, muscular dystrophy, arthritis, etc.** (Unacceptable: Victim. People with disabilities do not like to be perceived as victims for the rest of their lives, long after any victimization has occurred.)

Has a disability, has a condition of (spina bifida, etc.), or **born without legs, etc.** (Unacceptable: Defective, defect, deformed, vegetable. These words are offensive, dehumanizing, degrading, and stigmatizing.)

Deaf. Deafness often refers to a person who has a total loss of hearing. **Hard of hearing** refers to a person who has a partial loss of hearing within a range from slight to severe. **Hard of hearing** also describes a person who communicates through speaking and speech-reading, and who usually has listening and hearing abilities adequate for ordinary telephone communication. Many hard-of-hearing individuals use a hearing aid. Deaf people are sometimes able to speak and speech-read, despite profound hearing loss. Most people who identify themselves as deaf also use sign language. (Unacceptable: Hearing impaired; deaf and dumb is as bad as it sounds. The inability to speak does not indicate lack of intelligence.)

Person who has a mental or developmental disability. (Unacceptable: Retarded, moron, imbecile, idiot. These are offensive to people who bear the label.)

Use a wheelchair or crutches; a wheelchair user; walks with crutches. (Unacceptable: Confined/restricted to a wheelchair; wheelchair bound. Most people who use a wheelchair or mobility devices do not regard them as confining. They are viewed as liberating, a means of getting around.)

Nondisabled; able to walk, see, hear, etc.; people who are not disabled. (Unacceptable: Healthy, when used to contrast with "disabled"—Healthy implies that the person with a disability is unhealthy. Many people with disabilities have excellent health. Normal—When used as the opposite of disabled, this implies that the person is abnormal. No one wants to be labeled as abnormal.)

A person who has (name of disability). Example: a person who has multiple sclerosis. (Unacceptable: Afflicted with, suffers from, a victim of—Most people with disabilities do not regard themselves as victim or afflicted or suffering continually. Afflicted—a disability is not an affliction.)

Preparing for Sign Language Interpreters

When hiring an interpreter for a presenter who is deaf or for making presentations to an audience that may include participants who are deaf, remember that the interpreter is there to facilitate communication. An interpreter is always a neutral, uninvolved party. Interpreters are part of the team meant to deliver accurate and intended messages given by all parties.

The more advance notice that is provided to the interpreter, the more prepared he/she will be. This process will allow the interpreter to have the proper time needed for a meeting or event and prevent "cold" interpreting. Time for preparation is essential to allow accurate dissemination of the intended messages to the audience.

In addition to the name and type of event, always provide the name of the event contact person and a phone number. Give the following information to the interpreter to enhance the quality of the interpreted meeting/event:

- Clear address and directions to the event and the location where the interpreter is to check-in.
- Correct spellings of all names of those speaking or performing.

- A summary of subjects that will be presented by each speaker. Provide copies of any handouts for the interpreter prior to the meeting or event.
- A list of terms, acronyms, and words that are specific to the discussion, such as the usage of IHS (Indian Health Service) or BIA (Bureau of Indian Affairs).
- Many times the names of tribes are difficult to interpret, so spellings or any abbreviated descriptions would be helpful.

If any information to be presented is in a language other than English, a written interpretation in English will be needed in advance. Any time you have lights on the presenter you will also need to have lights for the interpreter, especially if the event is inside an auditorium or in any dark area.

Resources Regarding Interpreters

Intertribal Deaf Council (IDC)
Web site: www.deafnative.com

IDC promotes the interests of deaf and hard-of-hearing members to advance issues related to social, educational, economic, and environmental well-being by fostering and enhancing their cultural, historical, and linguistic tribal traditions.

The National Association of the Deaf (NAD)
814 Thayer Avenue
Silver Spring, MD 20910-4500
Phone: (301) 587-1788
TTY: (301) 587-1789
Fax: (301) 587-1791
Web site: www.nad.org/openhouse/affiliates/SAs.html

The NAD is a private, nonprofit constituency organization with affiliates in each state and the District of Columbia. A complete listing of state associations can be found at the NAD Web site. Programs and activities of the NAD include grassroots advocacy and empowerment; captioned media; certification of American Sign Language professionals; certification of sign language interpreters; deafness-related information and publications; legal assistance; policy development and research; public awareness; and youth leadership development.

Registry of Interpreters for the Deaf, Inc. (RID)
333 Commerce Street
Alexandria, VA 22314
Voice: (703) 838-0030
TTY: (703) 838-0459
Fax: (703) 838-0454

RID is a national nonprofit association for sign language interpreters with over 50 state and local affiliate offices. For additional guidance in working with an interpreter, instructions on how to hire an interpreter, or links to finding an interpreter, see the RID Web site.

Service Animals

Over 12,000 people with disabilities in the United States use service animals; many of those people are in tribal communities. It is important to know about service animals and to find ways to ensure safe and comfortable access for people with disabilities in tribal communities to be accompanied by these vitally important aids. Service animals should be accommodated in tribal, federal, and other public buildings in tribal communities. Tribal housing developments should also consider ways to ensure adequate access for people with disabilities who use service animals. Although the most familiar types of service animals are guide dogs used by people who are blind, service animals assist persons who have other disabilities as well. Many disabling conditions are invisible. A service animal is *not* required to have any special certification.

What Is a Service Animal?

A service animal is *not* a pet!

According to ADA, a service animal is any animal that has been individually trained to provide assistance or perform tasks for the benefit of a person with a physical or mental disability that substantially limits one or more major life functions

Service animals/service dogs can be trained to reliably perform many tasks, including the following:

- **Leading** a person who has a visual impairment around obstacles, to destinations (seating, across street, to/through door, to/into elevator, etc.).

- **Sound discrimination** to alert a person who is deaf or hard of hearing to the presence of specific sounds, such as
  - — Smoke/fire/clock alarms
  - — Telephone
  - — Baby crying
  - — Sirens
  - — Another person
  - — Timers buzzing
  - — Knocks at door
  - — Unusual sounds (e.g., things that go bump in the night, mice in the cabinet)

- **General assistance**, including
  - — Mobility (helping person balance for transfer/ambulation, pulling wheelchair, helping person rise from sitting or fallen position)
  - — Retrieval (getting items that are dropped or otherwise out of reach, carrying items by mouth)
  - — Scent discrimination (locate items; people; places, such as bathrooms, elevators, escalators, return path)
  - — Miscellaneous (e.g., open/close doors and drawers, help person undress/dress, carry items in backpack, act as physical buffer to jostling by others, put clothes in washer/remove from dryer, bark to alert for help)

- **Sense and alert** owners to oncoming seizures. It is currently unknown why or how some dogs are able to do this, but a number of dogs have demonstrated the ability to warn their owners of oncoming seizures, enabling the owners to position themselves safely.

- **Emotional support**, providing a known, trusting entity to facilitate homeostasis (e.g., maintenance of blood pressure, respiration, heart rate, temperature) during potentially difficult episodes. (Delta Society, 2002)

Service Animal Access

The civil rights of persons with disabilities to be accompanied by their service animals in all places of public and housing accommodations is protected by the following federal laws:

- Americans with Disabilities Act (1990)
- Air Carrier Access Act (1986)
- Fair Housing Amendments Act (1988)
- Rehabilitation Act (1973)

Service Animal Etiquette

- Do not touch the service animal, or the person it assists, without permission.
- Do not make noises at the service animal; they may distract the animal from doing its job.
- Do not feed the service animal; doing so may disrupt its schedule.
- Do not be offended if the person does not feel like discussing his/her disability or the assistance the service animal provides. Not everyone wants to be a walking show-and-tell exhibit.

Service Animal Resources

The Delta Society
580 Naches Avenue SW, Suite 101
Renton, WA 98055-2297
Phone: (425) 226-7357
Fax: (425) 235-1076
E-mail: info@deltasociety.org

The Delta Society is the leading international resource for the human-animal bond. The Delta Society has been the force to validate the important role of animals for people's health and well-being by promoting the results of research to the media and health and human services organizations.

Canine Companions for Independence
National Headquarters & Northwest Regional Center
2965 Dutton Avenue
PO Box 446
Santa Rosa, CA 95402-0446
Phone: (707) 577-1700
TDD: (707) 577-1756
E-mail: info@caninecompanions.org

Dogs for the Deaf
10175 Wheeler Road
Central Point, OR 97502
Voice/TDD: (541) 826-9220
Fax: (541) 826-6696
E-mail: info@dogsforthedeaf.org

Dogs for the Deaf's mission is to rescue and professionally train dogs to assist people and enhance their lives. Hearing dogs are chosen from adoption shelters, where they might otherwise be euthanized if no homes are found for them. By using shelter dogs, Dogs for the Deaf is able to help alleviate some of the unwanted dog population by rescuing these dogs, training them, and placing them in loving homes where they can provide an important service. The dogs are usually mixed breeds, small to medium in size, and up to 24 months of age. The trainers look for dogs that are friendly, energetic, healthy, and intelligent. Each dog is individually evaluated by a Dogs for the Deaf trainer. Those passing the aptitude tests are brought back to the facility for a thorough medical evaluation and needed vaccinations. All dogs are spayed or neutered and then begin the intensive 4 to 6 months of training.

References

City of San Antonio Disability Access Office/Planning Department. (2000). Disability Etiquette Handbook.

Delta Society. (2002). The Human-Animal Health Connection. Retrieved October 24, 2002, from www.deltasociety.org/dsb300.htm#tasks.

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

NOTICE

Reproduction Basis

X	This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.
	This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").